



END OF LIFE CARE BIBLIOGRAPHY JANUARY 2004

1: Acad Emerg Med. 2004 Jan;11(1):79-86.

End-of-life Models and Emergency Department Care.

Chan GK.

University of California, San Francisco, Department of Physiological Nursing,
San Francisco, CA.

Many people die in emergency departments (EDs) across the United States from sudden illnesses or injuries, an exacerbation of a chronic disease, or a terminal illness. Frequently, patients and families come to the ED seeking lifesaving or life-prolonging treatment. In addition, the ED is a place of transition—patients usually are transferred to an inpatient unit, transferred to another hospital, or discharged home. Rarely are patients supposed to remain in the ED. Currently, there is an increasing amount of literature related to end-of-life care. However, these end-of-life care models are based on chronic disease trajectories and have difficulty accommodating sudden-death trajectories common in the ED. There is very little information about end-of-life care in the ED. This article explores ED culture and characteristics, and examines the applicability of current end-of-life care models.

PMID: 14709435 [PubMed - in process]

2: Adv Mind Body Med. 2003 Summer;19(2):24-7.

A model of hypnotic intervention for palliative care.

Marcus J, Elkins G, Mott F.

Mind-Body Cancer Research Program & Center for Cancer Care and Prevention,
Texas
A&M University, System Health Science Center, College of Medicine, USA.

The World Health Organization defines palliative care as "the active total care of patients whose disease is not responsive to curative treatment." One of the primary issues of palliative care for patients with advanced cancer is symptom control and quality-of-life issues. The purpose of the hypnotic model presented here is to improve the patient's total psychological, social, and spiritual

well-being. There exists a need for a broad and inclusive model of mind-body interventions for palliative care. This is supported by the observation that symptoms related to psychological distress and existential concerns are even more prevalent than pain and other physical symptoms among those with life-limiting conditions. The following model integrates naturalistic, solution-oriented hypnosis within the framework of a situational 4-stage crisis matrix. The four stages of the matrix are: (1) The Initial Crisis, (2) Transition, (3) Acceptance, and (4) Preparation for Death. Hypnotic interventions are tailored to each stage in the crisis matrix.

Publication Types:

Review
Review, Tutorial

PMID: 14579808 [PubMed - indexed for MEDLINE]

3: Adv Nurse Pract. 2003 Aug;11(8):16-7.

Medicare rules on current role of NPs in hospice care.

Rollet J.

Publication Types:

News

PMID: 13677074 [PubMed - indexed for MEDLINE]

4: Am J Crit Care. 2003 Nov;12(6):558-61.

Attending death as a human passage: core nursing principles for end-of-life care.

Benner P, Kerchner S, Corless IB, Davies B.

School of Nursing, Department of Social and Behavioral Sciences, University of California, San Francisco, Calif., USA.

PMID: 14619363 [PubMed - in process]

5: Am J Crit Care. 2003 Jul;12(4):317-23; discussion 324.

Improving family communications at the end of life: implications for length of stay in the intensive care unit and resource use.

Ahrens T, Yancey V, Kollef M.

Barnes-Jewish Hospital, St. Louis, Mo., USA.

BACKGROUND: Inadequate communication persists between healthcare professionals

and patients and patients' families in intensive care units. Unwanted or ineffective treatments can occur when patients' goals of care are unknown or not honored, increasing costs and care. Having the primary physician provide medical information and then having a physician and clinical nurse specialist team improve opportunities for patients and their families to process that information could improve the situation. This model has not been tested for its effect on patients' outcomes and resource utilization. OBJECTIVES: To evaluate the effect of a communication team that included a physician and a clinical nurse specialist on length of stay and costs for patients near the end of life in the intensive care unit. METHODS: During a 1-year period, patients judged to be at high risk for death (N = 151) were divided into 2 groups: 43 patients who were cared for by the medical director teamed with a clinical nurse specialist and 108 patients who received standard care, provided by an attending physician. RESULTS: Compared with the control group, patients in the intervention group had significantly shorter stays in both the intensive care unit (6.1 vs 9.5 days) and the hospital (11.3 vs 16.4 days) and had lower fixed (\$15,559 vs \$24,080) and variable (\$5087 vs \$8035) costs. CONCLUSIONS: Use of a physician and a clinical nurse specialist focused on improving communication with patients and patients' families reduced lengths of stay and resource utilization.

PMID: 12882061 [PubMed - indexed for MEDLINE]

6: Am J Geriatr Cardiol. 2003 Jul-Aug;12(4):275-6.

When is deactivation of artificial pacing and AICD illegal, immoral, and unethical?

Silveira MJ.

Publication Types:
Case Reports
Letter

PMID: 14619876 [PubMed - indexed for MEDLINE]

7: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):340-4.

End-of-life care education in United States pharmacy schools.

Herndon CM, Jackson K 2nd, Fike DS, Woods T.

Division of Clinical Affairs, Ortho-McNeil Pharmaceutical Co., Lubbock, Texas, USA.

Hospice and palliative care have undergone dramatic changes in the past 30 years. Educational initiatives and certification programs for physicians (American Board of Hospice and Palliative Medicine) and nurses (National Board for Certification of Hospice and Palliative Nurses) have further delineated this area of practice as distinct from geriatrics, neurology, anesthesiology, or oncology. As other professions assess their own practices of hospice and end-of-life (EOL) care education in their respective schools and colleges, the

pharmacy profession must also ensure that its future graduates are prepared to adequately participate in this type of care. This was a descriptive study in which all accredited schools and colleges of pharmacy in the US were queried regarding their level of curricular commitment to EOL care. Eighty-three questionnaires were mailed, and 60 schools responded (72 percent). Four primary informational items regarding EOL and palliative care education were targeted, including availability of didactic teaching, specialization of pharmacy faculty, availability and type of clerkships, and method of instruction. Sixty-two percent of respondents indicated EOL care education was provided didactically (3.89 +/- 1.91 lecture hours per year). Fifty-eight percent of respondents indicated that EOL care experiential clerkships were available (4.97 +/- 1.25 weeks in duration). These data indicate that over half of US pharmacy students receive some exposure to EOL care education.

PMID: 14529036 [PubMed - indexed for MEDLINE]

8: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):329-30.

Comment on:

Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):353-9.

Advance directives: burden or benefit?

Enck RE.

Publication Types:

Comment

Editorial

PMID: 14529032 [PubMed - indexed for MEDLINE]

9: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):331-3.

Interdisciplinary teamwork in palliative care and hospice settings.

Rock W.

Dean Health Systems, Madison, Wisconsin, USA.

Publication Types:

Review

Review, Tutorial

PMID: 14529033 [PubMed - indexed for MEDLINE]

10: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):334.

Comment on:

Am J Hosp Palliat Care. 2003 Jul-Aug;20(4):259-61.

Reducing obstacles to rural hospice care.

Kyle M.

Publication Types:

Comment

Letter

PMID: 14529034 [PubMed - indexed for MEDLINE]

11: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):334.

Comment on:

Am J Hosp Palliat Care. 2003 May-Jun;20(3):229-30.

Guidelines for breakthrough pain dosing.

Davis MP.

Publication Types:

Comment

Letter

PMID: 14529035 [PubMed - indexed for MEDLINE]

12: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):360-70.

Satisfaction of families using end-of-life care: current successes and challenges in the hospice industry.

Miceli PJ, Mylod DE.

Research and Development Department, Press Ganey Associates, Inc., South Bend, Indiana, USA.

This study examined the satisfaction of family members with the end-of-life care their loved ones received. Data were collected from 1,839 individuals receiving care from 17 different care agencies nationwide. Although family satisfaction with hospice care was generally quite high, situational factors played a role. The timing of the referral was critical, with families rating services lower almost across the board when the referral to hospice was deemed "too late." Additionally, families expressed greater satisfaction when the patient's care was overseen by the hospice director, rather than a personal physician. Each of these findings has important implications for physicians, patients, and families as they begin to plan for end-of-life care.

PMID: 14529039 [PubMed - indexed for MEDLINE]

13: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):345-52.

The business of palliative medicine--Part 3: The development of a palliative medicine program in an academic medical center.

Nelson KA, Walsh D.

Cancer Treatment Research Foundation, Arlington Heights, Illinois, USA.

Palliative medicine is the total continuing care of patients with cancer. Most resources for cancer care focus on curative attempts while often ignoring the symptoms created by the disease and its treatment. Attempts at curative treatment of the malignancy must be coupled with pain and symptom relief psychosocial and spiritual care, and support for the patient and family extending from the time of diagnosis through the bereavement period. To accomplish this important goal, we must establish comprehensive palliative medicine programs in cancer centers throughout the world. These programs must include education, research, and patient care and must work through an interdisciplinary team. The Cleveland Clinic Foundation palliative medicine program (PMP) is composed of a primary inpatient service, consult service, outpatient clinic, hospice homecare, and cancer homecare services. In this article, we describe the structure and development of the program and suggest future avenues for growth.

PMID: 14529037 [PubMed - indexed for MEDLINE]

14: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):353-9.

Comment in:

Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):329-30.

Advance care planning among residents in long-term care.

McAuley WJ, Travis SS.

Health Behavior and Administration, College of Health and Human Services, University of North Carolina, Charlotte, North Carolina, USA.

This study was conducted to determine whether two types of advance directives exist for individuals residing in long-term care facilities. Findings were based on data from the Medical Expenditure Panel Study-Nursing Home Component (MEPS-NHC), a survey using a two-stage stratified probability sample of nursing homes and residents to produce valid national estimates of the nursing home population in the United States. The two types of advance directives included basic, i.e., living will or do-not-resuscitate (DNR) order, and progressive (do-not-hospitalize order or orders restricting feeding, medication, or other treatment). Approximately 59 percent of long-term care residents had a basic advance directive, 9 percent have a progressive directive, and 60 percent have some type of directive. Logistic regression results indicate that the factors associated with the likelihood of each type of directive differ considerably, and only two variables (African American ethnicity and less time in the facility) were associated with a reduced likelihood of having either type of directive. Our results indicate that the two proposed types of advance

directives are distinct with regard to the variables predicting each.

PMID: 14529038 [PubMed - indexed for MEDLINE]

15: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):371-81.

An analysis of provider attitudes toward end-of-life decision-making.

Rutsohn P, Ibrahim N.

Graduate School of Management, Marshall University, South Charleston, West Virginia, USA.

The explosion of technological and biomedical interventions over the past half century appears to have enhanced the medical profession's ability to prolong life at a faster pace than society's ability to develop comprehensive bioethical laws governing end-of-life decisions. This study was conducted to determine if there was a correlation between educational and occupational backgrounds and participants' perceptions of end-of-life care. Study participants came from various areas and levels of healthcare at a large federal healthcare facility and included nurses, doctors, pharmacists, dietitians, administrators, and others. Participants completed a questionnaire providing both sociodemographic information and perceptions of end-of-life care. Respondents were classified by type of education or background (technical, professional, or medical) and by level of involvement with patient care (direct or indirect). While the results showed a general consensus about the importance of respecting patients' end-of-life wishes, there were differences among respondents in regard to specific issues.

PMID: 14529040 [PubMed - indexed for MEDLINE]

16: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):382-8.

Toward evidence-based prescribing at end of life: a comparative review of temazepam and zolpidem for the treatment of insomnia.

Bain KT, Weschules DJ, Knowlton CH, Gallagher R.

ExcellerRx, Inc., Philadelphia, Pennsylvania, USA.

A comparative review of temazepam and zolpidem use in managing insomnia in the hospice patient was undertaken to determine whether treatment with temazepam is a more cost-effective approach for this patient population. A MEDLINE search was conducted to identify pertinent literature, including clinical trials and reviews that involved temazepam or zolpidem. Published data was used as background information and provided in the discussion. This retrospective analysis, conducted from June 2002 through November 2002, focused on the prescribing patterns of temazepam and zolpidem in our hospice practice setting. We examined the reasons for discontinuation of each agent, along with the frequency of therapeutic change from temazepam to zolpidem. The top 10 ICD-9 codes associated with each treatment modality were investigated to determine any

prescribing patterns. A total of 4,752 participants were prescribed either temazepam or zolpidem during this six-month period. Of the 4,065 patients prescribed temazepam 9.9 percent had the agent discontinued, whereas, 13.0 percent of those taking zolpidem (n = 687) terminated therapy. Reasons for discontinuation included change in dose, incomplete efficacy, change in patient status, adverse drug reaction, cultural/social issues and "other." Analyses of prescribing patterns and the reasons for termination of each drug therapy were completed and compared with results found in the primary literature. Due to the limited financial resources available for hospice care, our goal is to provide the most clinically appropriate and cost-effective agents for hospice patients. With the lack of data pertaining to the hospice patient, physicians often are faced with challenges in deciding the most appropriate therapy. They may prefer one agent over another based on current medical opinion rather than sound clinical evidence. After review of the primary literature and the prescribing patterns in our setting, there is currently no evidence in our patient population to support that zolpidem is superior to benzodiazepines for the treatment of insomnia.

Publication Types:
Meta-Analysis

PMID: 14529041 [PubMed - indexed for MEDLINE]

17: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):389-91.

Treatable complications of cancer patients referred to an in-patient hospice.

Morita T, Tei Y, Shishido H, Inoue S.

Seirei Hospice, Seirei Mikatabara Hospital, Shizuoka, Japan.

This paper illustrates the importance of accurate diagnoses and treatments of complications in terminally ill cancer patients. The paper reports on five hospice in-patients who completely recovered from life-threatening complications; three of them had been incorrectly labeled as "imminently dying" by the referring physicians. The paper concludes that it would be beneficial for patients to receive examinations and a trial of medical treatment in their continuing treatment settings.

Publication Types:
Case Reports

PMID: 14529042 [PubMed - indexed for MEDLINE]

18: Am J Hosp Palliat Care. 2003 Sep-Oct;20(5):393-4.

Questions, answers, and the bridge of language.

Noonan O.

Martha Jefferson Hospital, Charlottesville, Virginia, USA.

PMID: 14529043 [PubMed - indexed for MEDLINE]

19: Am J Law Med. 2003;29(2-3):301-17.

Dying children and medical research: access to clinical trials as benefit and burden.

Oberman M, Frader J.

DePaul University College of Law, USA.

Publication Types:
Historical Article

PMID: 12961809 [PubMed - indexed for MEDLINE]

20: Am J Law Med. 2003;29(1):45-76.

Terminal sedation: palliative care for intractable pain, post Glucksberg and Quill.

McStay R.

Methodist Hospital, Houston, Texas, USA.

Publication Types:
Legal Cases
Review
Review, Academic

PMID: 12953318 [PubMed - indexed for MEDLINE]

21: Am J Nurs. 2003 Nov;103(11):48-51, 54-8; quiz 59.

End-of-life care of older adults.

Sheehan DK, Schirm V.

Palliative Care Program, the Breen School of Nursing, Ursuline College, Pepper Pike, OH, USA. denicesheehan@adelphia.net

Publication Types:
Case Reports
Review
Review, Tutorial

PMID: 14625425 [PubMed - in process]

22: Arch Intern Med. 2003 Dec 8-22;163(22):2689-94.

Do-not-resuscitate orders and medical futility.

Cantor MD, Braddock CH 3rd, Derse AR, Edwards DM, Logue GL, Nelson W, Prudhomme AM, Pearlman RA, Reagan JE, Wlody GS, Fox E; Veterans Health Administration National Ethics Committee.

National Center for Ethics in Health Care of the Veterans Health Administration, Washington, DC 20420, USA.

This report addresses the difficult situation in which a patient or surrogate decision maker wishes cardiopulmonary resuscitation to be attempted even though the physician believes that resuscitation efforts would be futile. It also reviews current controversies surrounding the subject of do-not-resuscitate (DNR) orders and medical futility, discusses the complex medical, legal, and ethical considerations involved, and then offers recommendations as a guide to clinicians and ethics committees in resolving these difficult issues. Conflicts over DNR orders and medical futility should not be resolved through a policy that attempts to define futility in the abstract, but rather through a predefined and fair process that addresses specific cases and includes multiple safeguards. As it examines these issues, the report focuses on the Veterans Health Administration (VHA). Current national VHA policy constrains physicians from entering a DNR order over the objection of a patient or surrogate even if the physician believes cardiopulmonary resuscitation to be futile. The VHA National Ethics Committee recommends that VHA policy be changed to reflect the opinions expressed in this report. The National Ethics Committee, which is composed of VHA clinicians and leaders, as well as veterans advocates, creates reports that analyze ethical issues affecting the health and care of veterans treated in the VHA, the largest integrated health care system in the United States. This report does not change or modify VHA policy.

Publication Types:

Review

Review Literature

PMID: 14662622 [PubMed - indexed for MEDLINE]

23: Arch Intern Med. 2003 Oct 27;163(19):2270-5.

Ethical challenges of partial do-not-resuscitate (DNR) orders: placing DNR orders in the context of a life-threatening conditions care plan.

Berger JT.

Winthrop University Hospital, Mineola, NY 11501, USA. jberger@winthrop.org

Do-not-resuscitate (DNR) orders are commonly found in treatment plans for patients near the end of life. Orders for partial resuscitation (eg, "do not intubate") have evolved from DNR orders. Although the ethics of DNR orders have

been widely examined in the medical literature, little has been written about the ethics of partial resuscitation. This article explores the ethical implications of partial DNR orders and identifies the need to develop care plans addressing life-threatening conditions for patients with DNR orders.

PMID: 14581244 [PubMed - indexed for MEDLINE]

24: Aust Crit Care. 2003 Aug;16(3):84-5.

Improving end-of-life care in the intensive care unit: are nurses involved?

Latour JM.

Publication Types:
Editorial

PMID: 14533210 [PubMed - indexed for MEDLINE]

25: BMC Med. 2003 Dec 23 [Epub ahead of print].

Hospital care for children and young adults in the last year of life: a population-based study.

Feudtner C, DiGiuseppe DL, Neff JM.

Background: To help design population-based pediatric palliative care services, we sought to describe the hospital care received in the last year of life by children and young adults who died, determine the proportion with complex chronic conditions (CCCs), and to test whether use of hospital services increased as the date of death drew nearer. Methods: For all deaths occurring under 25 years of age from 1990 to 1996 in Washington State, we linked death certificate information to hospital utilization records and analyzed the timing and duration of hospitalizations, and the nature of hospital procedures, during the year prior to death. Results: Of the 8893 deaths, 25% had CCCs. Among infants with CCCs, 84% were hospitalized at the time of death, and 50% had been mechanically ventilated during their terminal admission. Among the 458 CCC-neonates dying under a week of age, 92% of all days of life were spent in the hospital; among the 172 CCC-neonates dying during the second to fourth weeks of life, 85% of all days of life were spent hospitalized; among the 286 CCC-infants dying during the second to twelfth month of life, 41% of all days of life were spent hospitalized. Among children and young adults with CCCs, 55% were hospitalized at the time of death, and 19% had been mechanically ventilated during their terminal admission. For these older patients, the median number of days spent in the hospital during the year preceding death was 18, yet less than a third of this group was hospitalized at any point in time until the last week of their lives. The rate of hospital use increased as death drew near. For subjects who had received hospital care, 44% had governmental insurance as the source of primary payment. Conclusions: Infants who died spent a substantial proportion of their lives in hospitals, whereas children and adolescents who died from CCCs predominantly lived outside of the hospital during the last year of life. To serve these patients, pediatric palliative and end-of-life care will

have to be provided in an integrated, coordinated manner both in hospitals and home communities.

PMID: 14690540 [PubMed - as supplied by publisher]

26: BMJ. 2003 Dec 13;327(7428):1406-7.

Comment on:

BMJ. 2003 Nov 1;327(7422):1011.

Adherence to advance directives: quality of life matters.

Yardley MH.

Publication Types:

Comment

Letter

PMID: 14670905 [PubMed - indexed for MEDLINE]

27: BMJ. 2003 Dec 13;327(7428):1407.

Comment on:

BMJ. 2003 Nov 1;327(7422):1011.

Adherence to advance directives: maybe doctors do not always know best.

Jones PS.

Publication Types:

Comment

Letter

PMID: 14670907 [PubMed - indexed for MEDLINE]

28: BMJ. 2003 Dec 13;327(7428):1407.

Comment on:

BMJ. 2003 Nov 1;327(7422):1011.

Adherence to advance directives: quality of life may be important in advance directives.

Shanks OE.

Publication Types:

Comment

Letter

PMID: 14670909 [PubMed - indexed for MEDLINE]

29: BMJ. 2003 Dec 13;327(7428):1406.

Comment on:

BMJ. 2003 Nov 1;327(7422):1011.

Adherence to advance directives: GMC's advance directive is commendable.

Higgs AG.

Publication Types:

Comment

Letter

PMID: 14670904 [PubMed - indexed for MEDLINE]

30: BMJ. 2003 Dec 13;327(7428):1407.

Comment on:

BMJ. 2003 Nov 1;327(7422):1011.

Br Med J (Clin Res Ed). 1987 Nov 14;295(6608):1221-2.

Adherence to advance directives: advance directive needs to include additional elements.

Knox GW.

Publication Types:

Comment

Letter

PMID: 14670910 [PubMed - indexed for MEDLINE]

31: BMJ. 2003 Nov 22;327(7425):1186.

Parliament to look again at issue of "assisted dying" for terminally ill patients.

Dyer O.

Publication Types:

News

PMID: 14630740 [PubMed - indexed for MEDLINE]

32: BMJ. 2003 Nov 22;327(7425):E256.

Comment in:

BMJ. 2003 Dec 13;327(7428):1404.

Oregon update.

Walsh E, Hendrickson S.

Oregon Health and Science, University Portland, USA. walshe@ohsu.edu

PMID: 14630782 [PubMed - indexed for MEDLINE]

33: BMJ. 2003 Nov 1;327(7422):1049.

Comment on:

BMJ. 2003 Jul 26;327(7408):204-6; discussion 206-7.

Responding to unexpected events: patients have to be treated as individuals.

Iwanowska HM.

Publication Types:

Comment

Letter

PMID: 14593058 [PubMed - indexed for MEDLINE]

34: BMJ. 2003 Nov 1;327(7422):1048.

What is a good death? Grandmother's death was a good example.

Kittel M.

Publication Types:

Letter

PMID: 14593056 [PubMed - indexed for MEDLINE]

35: BMJ. 2003 Nov 1;327(7422):1048.

What is a good death? Good death may be possible in emergency departments.

Ganstal AI.

Publication Types:

Letter

PMID: 14593053 [PubMed - indexed for MEDLINE]

36: BMJ. 2003 Nov 1;327(7422):1011.

Comment in:

BMJ. 2003 Dec 13;327(7428):1406.
BMJ. 2003 Dec 13;327(7428):1406-7.
BMJ. 2003 Dec 13;327(7428):1407.
BMJ. 2003 Dec 13;327(7428):1407.
BMJ. 2003 Dec 13;327(7428):1407.

Adherence to advance directives in critical care decision making: vignette study.

Thompson T, Barbour R, Schwartz L.

Division of Primary Health Care, University of Bristol, Bristol BS6 6JL.
trevor.thompson@bristol.ac.uk

OBJECTIVE: To explore health professionals' decision making in a critical care scenario when there is an advance directive. **DESIGN:** Qualitative study. **SETTING:** Scotland. **PARTICIPANTS:** Interviewees (n = 12) comprising general practitioners, hospital specialists, and nurses, and six focus groups (n = 34 participants) comprising general practitioners, geriatricians (consultants and specialist registrars), hospital nurses, and hospice nurses. **RESULTS:** When presented with an advance directive that applied to the same hypothetical scenario, health professionals came to divergent conclusions as to the "right thing to do." Arguments opposing treatment centred on the supremacy of autonomy as an ethical principle. Other arguments were that the decision to treat was consistent with the terms of the advance directive, or that, notwithstanding the advance directive, the patient's quality of life was sufficient to warrant treatment. **CONCLUSION:** Advance directives are open to widely varying interpretation. Some of this variability is related to the ambiguity of the directive's terminology whereas some is related to the willingness of health professionals to make subjective value judgments concerning quality of life.

PMID: 14593032 [PubMed - indexed for MEDLINE]

37: Can Fam Physician. 2003 Dec;49:1626-31.

Ethical issues in palliative care. Views of patients, families, and nonphysician staff.

Towers A, MacDonald N, Wallace E.

Palliative Care Division, McGill University Health Centre, Royal Victoria Hospital, Montreal, QC. anna.towers@muhc.mcgill.ca

OBJECTIVE: Much of what we know about ethical issues in palliative care comes from the perceptions of physicians and ethicists. In this study our goal was to hear other voices and to gain first-hand knowledge of the possibly contrasting views of patients, their families, nurses, volunteers, and other team members on end-of-life issues. **DESIGN:** Qualitative study using semistructured interviews. **SETTING:** Inpatient and consultation palliative care service of the Royal

Victoria Hospital in Montreal, Que. PARTICIPANTS: Of 113 people interviewed, 13 were patients, 43 were family members, 32 were volunteers, 14 were nurses, and 11 were other staff. METHOD: Interviewers elicited subjects' perspectives on ethical issues. Content analysis was used to identify, code, and categorize themes in the data. MAIN FINDINGS: Communication difficulties and insufficient resources and staff were the most frequently mentioned problems in this palliative care setting. CONCLUSION: The findings of this study will help guide policy decisions and setting of educational priorities in end-of-life care, particularly regarding the importance of adequate communication.

PMID: 14708928 [PubMed - in process]

38: Cancer. 2004 Jan 1;100(1):183-91.

Suicidality in terminally ill Japanese patients with cancer.

Akechi T, Okuyama T, Sugawara Y, Nakano T, Shima Y, Uchitomi Y.

Division of Psycho-Oncology, National Cancer Center Research Institute East, Kashiwa, Japan.

BACKGROUND: The risk of suicide is higher in patients with cancer than in the general population, making end-of-life care of suicidal terminal patients with cancer critical. To identify factors and longitudinal changes associated with suicidality among terminally ill Japanese patients with cancer, a prospective cohort study was performed. METHODS: Consecutive outpatients with cancer who registered with a palliative care unit participated. Structured interviews (e.g., Structured Clinical Interview for DSM- III-R [SCID]) were conducted to assess patient suicidal ideation (Ideation) and interest in requesting euthanasia (Interest) as main outcome measures of suicidality. Possible correlated factors also were investigated. The authors analyzed the data from 140 terminally ill patients with cancer at initial study participation (baseline) whose subsequent survival time was < 6 months. Of these 140 patients, 57 (40.7%) completed the follow-up assessment after admission to the unit. RESULTS: At baseline, 8.6% of the patients had Ideation and 5.0% had Interest. Self-reported anxiety and depression was significantly associated with Ideation (P= 0.003). Changes in Ideation and Interest occurred in 38.6% and 15.8% of the patients, respectively. Ideation was more likely to change than Interest (P = 0.006). The current study did not identify factors that predict changes and occurrences of suicidal ideation and interest in requesting euthanasia. CONCLUSIONS: Suicidality can change even in terminally ill patients. End-of-life care that focuses on the psychologic distress of dying individuals may be a way of preventing suicide. Copyright 2003 American Cancer Society.

PMID: 14692039 [PubMed - in process]

39: Cancer. 2003 Dec 1;98(11):2502-10.

Attitudes of medical oncologists toward palliative care for patients with advanced and incurable cancer: report on a survey by the European Society of Medical Oncology Taskforce on Palliative and Supportive Care.

Cherny NI, Catane R; European Society of Medical Oncology Taskforce on Palliative and Supportive Care.

Medical Oncology and Palliative Medicine Service, Department of Oncology, Shaare Zedek Medical Center, Jerusalem, Israel. chernyn@netvision.net.il

BACKGROUND AND METHODS: In part of a quality improvement program, the European Society of Medical Oncology (ESMO) surveyed its membership regarding their involvement in and attitudes toward the palliative care (PC) of patients with advanced cancer. **RESULTS:** Of 895 members who responded, 82.5% were European and 12.1% were American. Sixty-nine percent of respondents reported that patients with advanced cancer constituted a major proportion of their practice; for 22% of respondents, patients with advanced cancer constituted most of their practice. Only a minority of respondents collaborated often with a PC care specialist (35%), a palliative home care service (38%), an in-patient hospice (26%), or a psychologist (33%). In response to questions regarding specific involvement in PC clinical tasks, respondents were involved more commonly in treating physical symptoms, such as pain (93%), fatigue (84%), and nausea/emesis (84%), than in managing psychological symptoms and end-of-life care issues, such as depression/anxiety (65%), existential distress (29%), or delirium (12%). Forty-three percent of respondents reported that they directly administered end-of-life care often, and 74% reported that they derived satisfaction from their involvement in end-of-life care. Overall, 88.4% of respondents endorsed the belief that medical oncologists should coordinate the end-of-life care for their patients, but a substantial minority (42%) felt that they were trained inadequately for this task. Positive attitudes toward PC were correlated highly with the degree of direct involvement in PC practice. Practitioners in private practice or teaching hospitals had substantially more positive attitudes regarding PC compared with physicians based in comprehensive cancer centers ($P < 0.05$). Although most of the responding medical oncologists expressed positive views regarding their involvement in the PC of patients with advanced cancer and dying patients, 15% of respondents had pervasively negative views. **CONCLUSIONS:** Most ESMO oncologists recognize the importance of PC and supportive care for patients with advanced cancer. Despite this, many are prepared inadequately for these tasks, and actual participation levels commonly are suboptimal. Copyright 2003 American Cancer Society.

PMID: 14635087 [PubMed - indexed for MEDLINE]

40: Cancer Invest. 2003;21(5):772-81.

Waiting for the platelet count to rise: negotiating care at the end of life.

Abraham JL.

Dana-Farber Cancer Institute, 44 Binney Street, Boston, MA 02115, USA.
jabrahm@partners.org

Oncologists play a crucial role in enabling patients at the end of life and their families to decide whether the burden of chemotherapy is worth the

benefit. Using language that displays their concern for providing ongoing care and that does not mistakenly imply withholding of effective therapies can ease the transition off chemotherapy. Providing accurate, timely prognostic information; exploring patients' hopes, goals, and values; helping them resume meaningful activities; meeting their health care proxies and discussing the advance care plan with them can all enhance the relationship with patients at the end of life and ease fears of abandonment.

Publication Types:

Review

Review, Tutorial

PMID: 14628435 [PubMed - indexed for MEDLINE]

41: Clin Chest Med. 2003 Dec;24(4):763-73.

Improving care for patients dying in the intensive care unit.

Rubinfeld GD, Curtis JR.

Division of Pulmonary and Critical Care Medicine, Harborview Medical Center, University of Washington, 325 Ninth Avenue, Seattle, WA 98104-2499, USA. nodrog@u.washington.edu

It is impossible for ICU clinicians to avoid caring for dying patients and their families. For many, this is an extremely rewarding aspect of their clinical practice. There is ample evidence that there is room to improve the care of patients who are near death in the ICU. Despite the considerable holes in our knowledge about optimal care of dying critically ill patients, there is considerable agreement on the general principles of caring for these patients and about how to measure the outcomes of palliative care in the ICU. Practical approaches to improving the quality of end-of-life care exist and should be implemented.

PMID: 14710703 [PubMed - in process]

42: Clin J Oncol Nurs. 2003 Sep-Oct;7(5):545-52.

Diffuse malignant pleural mesothelioma: Part II. Symptom management.

Cordes ME, Brueggen C.

cordes.mary@mayo.edu

Patients with diffuse malignant pleural mesothelioma (DMPM) experience multiple symptoms from their disease and treatment, which can affect all aspects of their lives. Dyspnea, cough, pain, fatigue, depression, weight loss, anorexia, and cachexia are the most common symptoms. Early, ongoing assessment and management of these symptoms are imperative to maximize quality of life for patients with DMPM.

Publication Types:
Review
Review, Tutorial

PMID: 14603551 [PubMed - indexed for MEDLINE]

43: Conn Med. 2003 Oct;67(9):531-4.

The role of advance directives and family in end-of-life decisions in critical care units.

Kavic SM, Atweh N, Possenti PP, Ivy ME.

Department of Surgery, Bridgeport Hospital, Yale-New Haven Health System, Bridgeport, CT, USA. skavic@yahoo.com

PURPOSE: To define the extent and nature of the End-of-Life (EOL) decision-making process in critically ill patients. **MATERIALS AND METHODS:** Retrospective review of all deaths in adult medical and surgical intensive care units of a tertiary care hospital over a one-year period. **RESULTS:** There were sixty-one deaths in the study period. The mean age was 68 years, and 30 patients (49%) were female. Nearly one-third of patients had advance directives: eight patients presented advance directives on hospital admission, and 10 families produced advance directives at EOL. Seventy-six percent were admitted to the ICU as Code I (full care) and 24% were Code II (selective modification of care). At EOL, 10 patients were Code I, 14 were Code II, and 38 were transitioned to Code III (comfort care only). In the Code III population, the change in code status was initiated by the family in 12 cases. **CONCLUSIONS:** In a substantial number of instances transitioned to comfort care at EOL, the family initiated the code-status change. Interestingly, in several cases the family initially withheld advance directives. Critically ill patients and their families are assuming an active role in EOL care.

PMID: 14619340 [PubMed - indexed for MEDLINE]

44: Conn Med. 2003 Sep;67(8):497-503.

Congestive heart failure and the elderly.

Boxer R, Yang SX, Hager WD.

University of Connecticut Center on Aging, Farmington, CT, USA.

As patients age, congestive heart failure becomes an increasingly important problem and accounts for up to 20% of hospital admissions for patients over 65 years. With technological improvements in the treatment of coronary artery disease, improved survival after myocardial infarction, and better hypertension therapy, patients are living longer, thus the need for successful management of older patients with chronic heart failure. The elderly, especially minorities, tend to be under-represented in congestive heart failure trials. This article

will focus on the care of the geriatric patient with congestive heart failure.

Publication Types:

Review
Review, Tutorial

PMID: 14587131 [PubMed - indexed for MEDLINE]

45: Crit Care Clin. 2003 Oct;19(4):789-810, viii.

End-of-life care in the critically ill geriatric population.

Mularski RA, Osborne ML.

Division Pulmonary and Critical Care Medicine, Oregon Health and Science University, 3181 S. W Sam Jackson Park Rd, L102, Portland, OR 97239, USA.

As the geriatric population in the United States increases and better management of chronic diseases improves survival, more elderly will become critically ill and potentially require treatment in an intensive care unit (ICU). Dan Callahan has written, "... we will live longer lives, be better sustained by medical care, in return for which our deaths in old age are more likely to be drawn out and wild." Although no health care provider hopes for a drawn out and wild death for elderly patients, many geriatric persons will succumb to disease and die after having chosen and received ICU care. Recent data suggest that, on average, 11% of Medicare recipients spend more than 7 days in the ICU within 6 months before death.

PMID: 14601720 [PubMed - indexed for MEDLINE]

46: Crit Care Clin. 2003 Oct;19(4):811-25.

Controversial issues in critical care for the elderly: a perspective from Canada.

Rocker G.

Dalhousie University, Halifax Infirmary, #4457, 1796 Summer Street, Halifax, Nova Scotia, B3H 3A7 Canada. gmrocker@is.dal.ca

Age alone does not at all preclude the possibility of warranted, effective, and successful intensive care. From a medical perspective, the key issue is the reversibility or otherwise of an acute illness and where this illness sits in the trajectory of that individual's life and possible death. It makes no more sense to admit a 19-year-old let alone a 91-year-old to an intensive care unit if intensive care cannot provide what is needed. Of paramount importance in our consideration of critical care for the elderly is a determination and an understanding of the many needs--medical, emotional, social, spiritual, psychologic--that elderly people have. By exploring them with compassion and sensitivity, we can establish whether the goals of care include critical care and the associated technology, or whether alternative and more conservative

approaches more closely reflect the values and preferences of an increasingly elderly population.

PMID: 14601721 [PubMed - indexed for MEDLINE]

47: Crit Care Clin. 2003 Oct;19(4):713-27.

Chronic obstructive pulmonary disease in geriatric critical care.

Heffner JE, Highland KB.

Pulmonary Division, 812 CSB, Medical University of South Carolina, 96 Jonathan Lucas Street, P.O. Box 250623, Charleston, SC 29425, USA. heffnerj@musc.edu

COPD is a progressive disorder that is punctuated in its later stages with acute exacerbations that present a risk for respiratory failure. COPD has a disproportionate impact on older patients. In the ICU, therapy is directed toward unloading fatigued respiratory muscles, treating airway infection, and prescribing bronchodilatory drugs. Most patients survive hospitalization in the ICU for an episode of respiratory failure. The severity of the underlying lung disease, however, underlies the poor outcomes of patients in terms of postdischarge survival and quality of life.

PMID: 14601716 [PubMed - indexed for MEDLINE]

48: Crit Care Med. 2003 Sep;31(9):2255-62.

Comment in:

Crit Care Med. 2003 Sep;31(9):2399-400.

Quality indicators for end-of-life care in the intensive care unit.

Clarke EB, Curtis JR, Luce JM, Levy M, Danis M, Nelson J, Solomon MZ; Robert Wood Johnson Foundation Critical Care End-Of-Life Peer Workgroup Members.

Center for Applied Ethics and Professional Practice, University of Washington, Seattle, USA.

OBJECTIVE: The primary goal of this study was to address the documented deficiencies in end-of-life care (EOLC) in intensive care unit settings by identifying key EOLC domains and related quality indicators for use in the intensive care unit through a consensus process. A second goal was to propose specific clinician and organizational behaviors and interventions that might be used to improve these EOLC quality indicators. **PARTICIPANTS:** Participants were the 36 members of the Robert Wood Johnson Foundation (RWJF) Critical Care End-of-Life Peer Workgroup and 15 nurse-physician teams from 15 intensive care units affiliated with the work group members. Fourteen adult medical, surgical, and mixed intensive care units from 13 states and the District of Columbia in the United States and one mixed intensive care unit in Canada were represented. **METHODS:** An in-depth literature review was conducted to identify articles that assessed the domains of quality of EOLC in the intensive care unit and general

health care. Consensus regarding the key EOLC domains in the intensive care unit and quality performance indicators within each domain was established based on the review of the literature and an iterative process involving the authors and members of the RWJF Critical Care End-of-Life Peer Workgroup. Specific clinician and organizational behaviors and interventions to address the proposed EOLC quality indicators within the domains were identified through a collaborative process with the nurse-physician teams in 15 intensive care units. MEASUREMENTS AND MAIN RESULTS: Seven EOLC domains were identified for use in the intensive care unit: a) patient- and family-centered decision making; b) communication; c) continuity of care; d) emotional and practical support; e) symptom management and comfort care; f) spiritual support; and g) emotional and organizational support for intensive care unit clinicians. Fifty-three EOLC quality indicators within the seven domains were proposed. More than 100 examples of clinician and organizational behaviors and interventions that could address the EOLC quality indicators in the intensive care unit setting were identified. CONCLUSIONS: These EOLC domains and the associated quality indicators, developed through a consensus process, provide clinicians and researchers with a framework for understanding quality of EOLC in the intensive care unit. Once validated, these indicators might be used to improve the quality of EOLC by serving as the components of an internal or external audit evaluating EOLC continuous quality improvement efforts in intensive care unit settings.

PMID: 14501954 [PubMed - indexed for MEDLINE]

49: EDTNA ERCA J. 2003 Jul-Sep;29(3):123-6.

Nursing terminally sick dialysis patients.

de Miguel B.

Hospital Universitario Germans Trias i Pujol Servicio de Nefrologia C/Carretera del Canyet, s/n Badalona 08916, Barcelona, Spain. bdemiguel61@hotmail.com

The number of terminally sick patients (TSP) in haemodialysis (HD) is rising. The personnel that assist these patients wonder if they are sufficiently qualified to help and care for them and if TSP require treatment that is different to the other chronic dialysis patients. The reason for this study was to investigate if caring for TSP psychologically affected the infirmary personnel who looked after them during HD.

PMID: 14552084 [PubMed - indexed for MEDLINE]

50: Eur J Cardiovasc Nurs. 2002 Dec;1(4):223-5.

End-of-life issues in cardiac patients and their families.

Jaarsma T, Leventhal M.

Department of Cardiology, University Hospital Groningen P.O. Box 30.001 9700 RB, Groningen, The Netherlands. t.jaarsm@thorax.azg.nl

PMID: 14622651 [PubMed - indexed for MEDLINE]

51: Health Qual Life Outcomes. 2003 Nov 7;1(1):65. Epub 2003 Nov 07.

Life at the end of life: beliefs about individual life after death and "good death" models - a qualitative study.

Toscani F, Borreani C, Boeri P, Miccinesi G.

Lino Maestroni Institute for Research in Palliative Medicine, Via Palestro 1, 26100 Cremona, Italy. toscani.f@dinet.it

BACKGROUND: Different ideas of "good death" may influence the effectiveness of end-of-life care in patients with different ethos. This study aimed to identify the influence of believing in individual life after death on "good death" models. **METHODS:** Semi structured-interview to 8 persons, 4 believers and 4 non-believers in individual life after death from the general Italian population. Analysis of the transcribed text according to the method suggested by Mc Cracken. **RESULTS:** The analysis has shown a diverse and coherent conceptualization of death according to whether the subjects believe or not in individual life after death. Believers, for whom death marks the passage to a new dimension, prefer to be unaware of dying, while non-believers, for whom death is the end of the individual, prefer to be conscious until the very end of life. However some important aspects in common have been identified, i.e. having close people nearby, receiving assistance from experts, or the preference for a soft atmosphere around the dying person. **CONCLUSION:** There are aspects in common and aspects in contrast between believers and non-believers in individual life after death: while sharing many aspects of what a "good death" ought to be, they have opposite stands on being aware of dying. A plurality of models should be foreseen, accepting, in this case, their practical and theoretical implications.

PMID: 14613557 [PubMed - as supplied by publisher]

52: Health Soc Care Community. 2004 Jan;12(1):43-52.

Carer satisfaction with end-of-life care in Powys, Wales: a cross-sectional survey.

Ingleton C, Morgan J, Hughes P, Noble B, Evans A, Clark D.

School of Nursing and Midwifery, University of Sheffield, UK, University of Sheffield, Sheffield, UK, Powys Health Care NHS Trust, Dyfed, Powys, UK and University of Lancaster, Lancaster, UK.

A cross-sectional postal survey of bereaved carers was conducted in order to examine levels of satisfaction with services provided for people in their last year of life in the rural county of Powys, Wales, UK. A self-complete questionnaire, using a modified version of the Views of Informal Carers - Evaluation of Services instrument was sent to all bereaved carers of all those people dying of cancer in Powys between 1 April 1999 and 30 June 2001. Eight

hundred and five (out of a possible of 815 people) were contacted and 407 agreed to receive the questionnaire. Out of these 407 individuals, 301 (74% of those who agreed to receive a questionnaire and 37% of the 815 contacted) returned a completed questionnaire. A single reminder letter was sent to non-responders. It was found that the majority of those who received help from district nurses or practice nurses (90%) said that they were excellent or good. However, nearly 40% of respondents reported needing more nursing help. More help was also needed from social care services. For 103 out of the 301 respondents, it was known that the deceased person wanted to die at home; only 44 did so. Only one-fifth of respondents had the opportunity to talk to someone from health and social services after their bereavement; a large majority (four-fifths) found this helpful. One-tenth of respondents reported untreated pain at home; however, there was evidence for an increasing proportion of those treated having received good pain relief. Although there are high levels of satisfaction with care and services received by Powys residents, deficits exist in relation to: symptom control, nursing help, assistance from social services with transport and bathing, communication, and bereavement support.

PMID: 14675364 [PubMed - in process]

53: Home Healthc Nurse. 2003 Nov;21(11):753-8; quiz 759-60.

Infection control update for home care and hospice organizations.

Friedman MM.

Home Health Systems, Inc., Marietta, GA 30066, USA. mmf@mindsping.com

PMID: 14614386 [PubMed - indexed for MEDLINE]

54: Home Healthc Nurse. 2003 Sep;21(9):629-32.

Learning to have difficult conversations leads to increased hospice referrals.

Pitorak EF.

Hospice Institute, Hospice of the Western Reserve, Cleveland, OH 44119, USA.
epitorak@hospicewr.org

PMID: 14534463 [PubMed - indexed for MEDLINE]

55: Hosp Health Netw. 2003 Nov;77(11):30.

Hospice care. Final reunions.

Joch A.

Publication Types:

News

PMID: 14669562 [PubMed - indexed for MEDLINE]

56: Int J Aging Hum Dev. 2003;56(2):155-70.

Preferences for prolonging life: a prospect theory approach.

Winter L, Lawton MP, Ruckdeschel K.

Thomas Jefferson University, Philadelphia, PA 19107, USA.
Laraine.Winter@Jefferson.edu

Kahneman and Tversky's (1979) Prospect theory was tested as a model of preferences for prolonging life under various hypothetical health statuses. A sample of 384 elderly people living in congregate housing (263 healthy, 131 frail) indicated how long (if at all) they would want to live under each of nine hypothetical health conditions (e.g., limited to bed or chair in a nursing home). Prospect theory, a decision model which takes into account the individual's point of reference, would predict that frail people would view prospective poorer health conditions as more tolerable and express preferences to live longer in worse health than would currently healthy people. In separate analyses of covariance, we evaluated preferences for continued life under four conditions of functional ability, four conditions of cognitive impairment, and three pain conditions--each as a function of participant's current health status (frail vs. healthy). The predicted interaction between frailty and declining prospective health status was obtained. Frail participants expressed preferences for longer life under more compromised health conditions than did healthy participants. The results imply that such preferences are malleable, changing as health deteriorates. They also help explain disparities between proxy decision-makers' and patients' own preferences as expressed in advance directives.

PMID: 14533855 [PubMed - indexed for MEDLINE]

57: Int J Palliat Nurs. 2003 Oct;9(10):439-41.

The Preferred Place of Care document: an opportunity for communication.

Pemberton C, Storey L, Howard A.

Lancashire and South Cumbria Cancer Services Networks, Preston Business Centre,
Watling Street Road, Fulwood, Preston, PR2 8DY, UK. chris.pemberton@clha.nhs.uk

Publication Types:
Editorial

PMID: 14593281 [PubMed - indexed for MEDLINE]

58: Int J Palliat Nurs. 2003 Oct;9(10):420-2.

Is it ever too late for holistic cancer care?

Daniel R.

Publication Types:
Editorial

PMID: 14593278 [PubMed - indexed for MEDLINE]

59: Int J Palliat Nurs. 2003 Sep;9(9):375-81.

Nurses' perceptions of the Liverpool Care Pathway for the dying patient in the acute hospital setting.

Jack BA, Gambles M, Murphy D, Ellershaw JE.

Edge Hill College School of Health Studies, University Hospital Aintree,
Longmore Lane, Liverpool, L9 7AL, UK.

The Liverpool Care Pathway for the dying patient (LCP) was developed to transfer the hospice model of care into other care settings. It is a multiprofessional document that provides an evidence-based framework for the dying phase. It provides guidance on the different aspects of care required including comfort measures, anticipatory prescribing of medication, and discontinuation of inappropriate interventions. Additionally, psychological and spiritual care and family support is included. This article presents the findings of a study to explore hospital nurses' perceptions of the impact of the LCP using focus group interviews. Data were analysed for emerging themes using thematic analysis. The results suggest that the nurses have generally found that the LCP had a positive impact on patients, their families and also on nurses and doctors. This article will explore these benefits, as well as potential barriers to its use.

PMID: 14593273 [PubMed - indexed for MEDLINE]

60: Int Urol Nephrol. 2002-2003;34(4):573-6.

The very elderly dialysis patient: indication and discontinuation of dialysis.

Schaefer K, von Herrath D, Faust J, Rohrich B.

St. Joseph-Krankenhaus, Medizinische Abteilung II, Baumerplan 24, 12101 Berlin, Germany.

1. When the current available data in the literature is summarized it becomes evident that the majority of it supports the position that it is, at least for medical reasons, not advisable to exclude patients over the age of 80 years from chronic dialysis. 2. It is correct to say that the refusal of dialysis therapy for elderly dialysis patients would lead to a not insignificant cutting of costs, although elderly patients are not as 'expensive' as younger dialysis patients. 3. The decision to exclude patients over 80 from dialysis treatment is

difficult, in our opinion, to support ethically. 4. The refusal of therapy by a dialysis patient--independent of his age--can only occur with his/her consent, as long as the patient is clearly conscious of the decision. 5. Should the patient no longer be in the condition to exercise his/her autonomy, and there is no AD, the Surrogate's Court must be consulted. 6. AD can be seen as helpful, since they not only make the decisions for physicians easier, but also because they can be seen as an act of care for family members. 7. Whenever dialysis therapy is discontinued the problematic nature of so-called essential care should be carefully considered, especially if no clear position has been taken in an AD.

PMID: 14577507 [PubMed - indexed for MEDLINE]

61: Intern Med J. 2003 Jul;33(7):265-6.

Opioids in palliative care: emerging clinical trends.

Ashby M, Jackson K.

Palliative Care Unit, Monash Medical Centre, Southern Health, Melbourne, Victoria, Australia.

PMID: 12823669 [PubMed - indexed for MEDLINE]

62: Isr Med Assoc J. 2003 Nov;5(11):770-4.

Forgoing life-sustaining treatments: comparison of attitudes between Israeli and North American intensive care healthcare professionals.

Soudry E, Sprung CL, Levin PD, Grunfeld GB, Einav S.

Medical Education Unit, Technion Faculty of Medicine, Haifa, Israel.

BACKGROUND: Physicians' decisions regarding provision of life-sustaining treatment may be influenced considerably by non-medical variables. **OBJECTIVES:** To examine physicians' attitudes towards end-of-life decisions in Israel, comparing them to those found in the United States. **METHODS:** A survey was conducted among members of the Israel Society of Critical Care Medicine using a questionnaire analogous to that used in a similar study in the USA. **RESULTS:** Forty-three physicians (45%) responded, the majority of whom hold responsibility for withholding or withdrawing life-sustaining treatments. Preservation of life was considered the most important factor by 31 responders (72%). The quality of life as viewed by the patient was generally considered less important than the quality of life as viewed by the physician. Twenty-one responders (49%) considered withholding treatment more acceptable than withdrawing it. The main factors for decisions to withhold or withdraw therapy were a very low probability of survival of hospitalization, an irreversible acute disorder, and prior existence of chronic disorders. An almost similar percent of physicians (93% for Israel and 94% for the U.S.) apply Do Not Resuscitate orders in their intensive care units, but much less (28% vs. 95%) actually discuss these orders with the families of their patients. **CONCLUSIONS:** Critical care physicians in

Israel place similar emphasis on the value of life as their U.S. counterparts and assign DNR orders with an incidence equaling that of the U.S. They differ from their U.S. counterparts in that they confer less significance to the will of the patient, and do not consult as much with families of patients regarding DNR orders.

PMID: 14650099 [PubMed - indexed for MEDLINE]

63: Issues Law Med. 2003 Fall;19(2):111-34.

Legal anxieties and end-of-life care in nursing homes.

Kapp MB.

Wright State University School of Medicine, Box 927, Dayton, OH 45401-0927, USA.
marshall.kapp@wright.edu

Many persons spend their final days as nursing home residents. It has been suggested that one set of factors powerfully and unfavorably influencing the quality of end-of-life (EOL) care provided in American nursing homes involves the anxieties that nursing home providers experience regarding potential negative legal entanglements and repercussions associated with the provision of EOL care to their residents. This article critically examines the hypothesis that the quality of EOL medical care provided in nursing homes often is skewed in a perverse way because providers are driven unduly by legal apprehensions. The author offers practice and policy recommendations for trying to resolve or mitigate the tension present between legally defensive practice (real or perceived) by nursing homes, on one hand, and ethically optimal EOL care, on the other.

PMID: 14708257 [PubMed - in process]

64: J Am Coll Surg. 2003 Nov;197(5):847-53; discussion 853-4.

The surgical intensivist as mediator of end-of-life issues in the care of critically ill patients.

Eachempati SR, Miller FG, Fins JJ.

Department of Surgery, Weill Medical College of Cornell University, New York, NY, USA.

Publication Types:

Case Reports

Review

Review, Tutorial

PMID: 14585423 [PubMed - indexed for MEDLINE]

65: J Am Geriatr Soc. 2003 Nov;51(11):1587-94.

End-of-life care in assisted living and related residential care settings:
comparison with nursing homes.

Sloane PD, Zimmerman S, Hanson L, Mitchell CM, Riedel-Leo C, Custis-Buie V.

Department of Family Medicine School of Social Work, University of North
Carolina at Chapel Hill, Chapel Hill, North Carolina 27599, USA.
psloane@med.unc.edu

OBJECTIVES: To define the current state of end-of-life care in residential care/assisted living (RC/AL) facilities and nursing homes (NHs) and to compare these two types of care settings. **DESIGN:** Interviews of staff and family informants about deaths that occurred during a longitudinal study. **SETTING:** Fifty-five RC/AL facilities and 26 NHs in Florida, Maryland, New Jersey, and North Carolina. **PARTICIPANTS:** Two hundred twenty-four staff and family informants that best knew the 73 RC/AL residents and 72 NH residents who died in or within 3 days after discharge from a study facility. **MEASUREMENTS:** Telephone interviews conducted with the facility staff member who knew the decedent best and the family member who was most involved in care during the last month of life of the decedent. Data were collected on circumstances of death, perceptions of dying process, cause of death, care during the last month of life, mood, discomfort, and family satisfaction. **RESULTS:** Most decedents died in the facility where they had resided, and more than half of the subjects were alone when they died. Greater proportions of staff and family in the NHs knew that the resident's death was only days or weeks away. Both RC/AL and NH residents experienced few highly negative moods, and even on their most uncomfortable day, the overall discomfort was low for residents in both facility types. Summary ratings of family satisfaction were significantly higher for the RC/AL (32.1) than the NH (41.2) group ($P=.016$). **CONCLUSION:** These data suggest that end-of-life care in RC/AL settings appears similar in process and outcomes to that provided in NHs. Thus, aging and dying-in-place can effectively occur in RC/AL.

PMID: 14687388 [PubMed - in process]

66: J Am Geriatr Soc. 2003 Oct;51(10):1502-3.

Comment on:

J Am Geriatr Soc. 2003 Oct;51(10):1435-8.

Regulating hearts and minds: the mismatch of law, custom, and resuscitation decisions.

Lynn J, Gregory CO.

Publication Types:

Comment
Editorial

PMID: 14511178 [PubMed - indexed for MEDLINE]

67: J Am Geriatr Soc. 2003 Oct;51(10):1435-8.

Comment in:

J Am Geriatr Soc. 2003 Oct;51(10):1502-3.

Prehospital DNR orders: what do physicians in Washington know?

Silveira MJ, Buell RA, Deyo RA.

General Medicine, Bioethics Program, University of Michigan, Ann Arbor, Michigan, USA. mariaajs@umich.edu

OBJECTIVES: To assess whether physicians know of Washington State's prehospital do-not-resuscitate (DNR) policy, 6 years after its implementation. **DESIGN:** Cross-sectional survey. **SETTING:** Washington State, April 2001. **PARTICIPANTS:** Four hundred seventy-one practicing physicians. **MEASUREMENTS:** Multivariate logistic regression was used to determine relationships between physician and practice characteristics with knowledge of policies governing advance care planning. **RESULTS:** Among respondents, 60% did not know that Washington State requires an emergency medical service (EMS)-specific DNR order authored by a physician. Seventy-nine percent did not know that patient-authored advance directives apply only in hospitals and medical offices. **CONCLUSION:** The findings in this study suggest that most physicians in Washington State lack knowledge about the documentation needed for EMS personnel to forgo pre-hospital attempts at cardiopulmonary resuscitation. Further study is needed to determine whether physician education or legislative change is necessary.

PMID: 14511164 [PubMed - indexed for MEDLINE]

68: J Am Med Dir Assoc. 2003 Sep-Oct;4(5):289-90.

Declaration of death: Position Statement of the American Medical Directors Association.

American Medical Directors Association.

PMID: 12959650 [PubMed - indexed for MEDLINE]

69: J Christ Nurs. 2003 Fall;20(4):25-8.

Medical futility. When is enough, enough?

Salladay SA.

Center for Bioethics, BryanLGH Medical Center, College of Health, Lincoln, Nebraska, USA.

Publication Types:

Case Reports

PMID: 14533583 [PubMed - indexed for MEDLINE]

70: J Clin Oncol. 2003 Dec 1;21(23):4463.

Comment on:

J Clin Oncol. 2003 Apr 1;21(7):1412-5.

When the tumor is not the target: a title whose time is up?

Abratt RP.

Publication Types:

Comment

Letter

PMID: 14645442 [PubMed - indexed for MEDLINE]

71: J Clin Oncol. 2003 Dec 1;21(23):4460-2.

Spirituality and religion in the "art of dying".

Ramondetta LM, Sills D.

Department of Gynecologic Oncology, Unit 440, The University of Texas M.D.
Anderson Cancer Center, 1515 Holcombe Blvd, Houston, TX 77030-4009, USA.
Iramonde@mdanderson.org

Publication Types:

Review

Review, Tutorial

PMID: 14645439 [PubMed - indexed for MEDLINE]

72: J Crit Care. 2003 Sep;18(3):141-4.

Commentary: observational studies and their importance in improving end-of-life care in the intensive care unit.

Engelberg RA.

Harborview Medical Center, Division of Pulmonary and Critical Care, Department
of Medicine, School of Medicine, Washington Seattle, WA 98104-2499, USA.
rengel@u.washington.edu

Publication Types:

Comment

PMID: 14626210 [PubMed - in process]

73: J Eval Clin Pract. 2003 Aug;9(3):363-72.

Barriers to physicians' decisions to discuss hospice: insights gained from the United States hospice model.

McGorty EK, Bornstein BH.

Department of Psychology, University of Nebraska-Lincoln, Lincoln, NE 68588-0308, USA.

Due to its comprehensive and cost-saving design, hospice has become a critical component of health care. Physicians have become the primary gatekeepers to information on hospice and sources of referral to hospice. However, many physicians do not discuss hospice options until late in the disease course, when patients and their families are no longer able to benefit from hospice services. Although physicians, as well as patients and hospice personnel, cite patient and hospice structure factors as barriers, the present article will focus on barriers physicians have more control over, such as their discomfort discussing terminality and fear of losing contact with patients. Focusing on the American hospice model, the present article will review past findings, examine gaps in the research, and propose systematic ways to discern whether the factors physicians claim are barriers actually affect their decision making about hospice referral.

Publication Types:

Review

Review, Tutorial

PMID: 12895158 [PubMed - indexed for MEDLINE]

74: J Gen Intern Med. 2003 May;18(5):343-9.

Comment in:

J Gen Intern Med. 2003 May;18(5):404-6.

Changes in the use of do-not-resuscitate orders after implementation of the Patient Self-Determination Act.

Baker DW, Einstadter D, Husak S, Cebul RD.

Center for Health Care Research and Policy and Department of Medicine, Case Western Reserve University at MetroHealth Medical Center, Cleveland, Ohio, USA. dwbaker@northwestern.edu

OBJECTIVE: To determine changes in the use of do-not-resuscitate (DNR) orders and mortality rates following a DNR order after the Patient Self-determination Act (PSDA) was implemented in December 1991. **DESIGN:** Time-series. **SETTING:** Twenty-nine hospitals in Northeast Ohio. **PATIENTS/PARTICIPANTS:** Medicare patients (N = 91,539) hospitalized with myocardial infarction, heart failure, gastrointestinal hemorrhage, chronic obstructive pulmonary disease, pneumonia,

or stroke. MEASUREMENTS AND MAIN RESULTS: The use of "early" (first 2 hospital days) and "late" DNR orders was determined from chart abstractions. Deaths within 30 days after a DNR order were identified from Medicare Provider Analysis and Review files. Risk-adjusted rates of early DNR orders increased by 34% to 66% between 1991 and 1992 for 4 of the 6 conditions and then remained flat or declined slightly between 1992 and 1997. Use of late DNR orders declined by 29% to 53% for 4 of the 6 conditions between 1991 and 1997. Risk-adjusted mortality during the 30 days after a DNR order was written did not change between 1991 and 1997 for 5 conditions, but risk-adjusted mortality increased by 21% and 25% for stroke patients with early DNR and late DNR orders, respectively. CONCLUSIONS: Overall use of DNR orders changed relatively little after passage of the PSDA, because the increase in the use of early DNR orders between 1991 and 1992 was counteracted by decreasing use of late DNR orders. Risk-adjusted mortality rates after a DNR order generally remained stable, suggesting that there were no dramatic changes in quality of care or aggressiveness of care for patients with DNR orders. However, the increasing mortality for stroke patients warrants further examination.

PMID: 12795732 [PubMed - indexed for MEDLINE]

75: J Health Law. 2003 Summer;36(3):455-73.

The disutility of advance directives: we know the problems, but are there solutions?

Hickey DP.

Medical College of Ohio, USA.

Advance directives (ADs) are recognized in some form by the laws of every state. Despite the availability of ADs for more than twenty years, few adults have completed any type of AD document. Even when ADs are validly executed, physicians routinely fail to honor patients' wishes. The lack of communication between physicians and patients may be the primary reason why AD completion rates remain so low. The failure to honor an AD may stem from the physician's belief that to honor a directive would not be in the patient's best interest. The adoption and enforcement by all states of the Uniform Health-Care Decisions Act, recognition of a physician's ethical duty to assist patients in AD formulation, and routine third-party payor reimbursement to physicians for their role in patients' advance care planning will encourage and facilitate the completion and subsequent honoring of patients' directives.

Publication Types:
Legal Cases

PMID: 14632382 [PubMed - indexed for MEDLINE]

76: J Law Med Ethics. 2003 Fall;31(3):365-76.

End-of-life care: forensic medicine v. palliative medicine.

Pestaner JP.

Riverside County Sheriff's Department, Coroner Bureau, Perris, California, USA.

Publication Types:

Review

Review, Tutorial

PMID: 14626545 [PubMed - indexed for MEDLINE]

77: J Neurosci Nurs. 2003 Oct;35(5):242-51.

Nursing care of patients with late-stage Parkinson's disease.

Calne SM, Kumar A.

Pacific Parkinson's Research Centre, Vancouver, BC, Canada.
scalne@interchange.ubc.ca

Patients in the late stages of Parkinson's disease may be significantly disabled for many years, often because of their increasing inability to tolerate therapeutic doses of antiparkinson drugs. Their status and management have been overlooked in the literature. Few current healthcare professionals have cared for patients with Parkinson's disease in the prelevodopa era and do not understand how severe and protracted the illness can be without effective treatment. This article describes a practical approach to the nursing management of severely affected patients (i.e., Hoehn and Yahr Stage 4-5) who no longer derive consistent, therapeutic benefit from their drugs. Specific problems these patients face are adverse drug reactions such as postural hypotension, psychosis, and confusion, as well as difficulties with nutrition, elimination, mobility and falling, communication, sexuality, memory, and mood. Nursing interventions can help minimize the effect of these problems on the patient.

Publication Types:

Review

Review, Tutorial

PMID: 14593935 [PubMed - indexed for MEDLINE]

78: J Nurs Scholarsh. 2003;35(3):249-55.

Nurses' attitudes and practice related to hospice care.

Cramer LD, McCorkle R, Cherlin E, Johnson-Hurzeler R, Bradley EH.

Yale School of Public Health, 60 College Street, New Haven, CT 06520-8034, USA.
elizabeth.bradley@yale.edu

PURPOSE: To describe characteristics, attitudes, and communications of nurses regarding hospice and caring for terminally ill patients. DESIGN: A cross-sectional study of randomly selected nurses (n = 180) from six randomly

selected Connecticut community hospitals was conducted in 1998 and 1999. METHODS: Hospice-related training, knowledge and attitudes, demographic and practice characteristics, and personal experience with hospice were assessed with a self-administered questionnaire (response rate = 82%). Logistic regression was used to model the effects of hospice-related training, knowledge, and attitudes on these outcomes, adjusting for personal experience and other characteristics of nurses. FINDINGS: Characteristics associated with discussion of hospice with both patients and families included greater religiousness, having a close family member or friend who had used hospice, and reporting satisfaction with hospice caregivers. Greater self-rated knowledge was significantly associated with discussion of hospice with patients. Attitudinal scores indicating greater comfort with initiating discussion and greater perceived added benefit of hospice were significantly associated with discussion with patients' families. CONCLUSIONS: Nurses' discussion of hospice with terminally ill patients and their families are related to the potentially modifiable factors of self-rated knowledge and attitudes revealing comfort with discussion and perceived benefit of hospice care.

PMID: 14562493 [PubMed - indexed for MEDLINE]

79: J Pain Palliat Care Pharmacother. 2003;17(2):71-82.

The Kansas Living Initiatives for End-of-Life Care.

Bales DM.

Kansas Life Project, USA. donna@lifeproject.org

The Kansas Living Initiatives for End-of-Life Care (LIFE) project was formed in 1999 by over 70 Kansas organizations, agencies and associations to further the cause of dignified, comfortable and peaceful end of life in terminally ill patients. LIFE developed a module on end-of-life care that was added to the Kansas year 2000 Behavioral Risk Factor Surveillance system, convened meetings of partners including health professional licensing boards, reviewed state laws and regulations, and published a joint policy statement of the Kansas Boards of Healing Arts, Nursing and Pharmacy on the use of controlled substances for pain management. Activities of Project LIFE and outcomes are described.

PMID: 14649390 [PubMed - indexed for MEDLINE]

80: J Pain Palliat Care Pharmacother. 2003;17(1):31-7.

The International Association for Hospice and Palliative Care: international activities and future initiatives.

De Lima L, Bruera E, Woodruff R.

International Association of Hospice and Palliative Care, Houston, TX 77030, USA. lidelima@aol.com

The International Association for Hospice and Palliative Care (IAHPC) is a

global organization dedicated to the development and improvement of palliative care. The mission of IAHPHC is to increase the availability and access to high quality hospice and palliative care for patients and families throughout the world. It does this by promoting communication, facilitating and providing education, and by becoming an information resource for patients, professionals, health care providers and policy makers around the world. This report describes activities of the IAHPHC throughout the world and planned future initiatives.

PMID: 14640338 [PubMed - indexed for MEDLINE]

81: J Pain Palliat Care Pharmacother. 2003;17(1):39-45.

Symptom-related research from the agency for healthcare research and quality.

Lipman AG.

College of Pharmacy and Director of Clinical Pharmacology, Pain Management Center, University of Utah Health Sciences Center, Salt Lake City, UT 84112-5820, USA. alipman@pharm.utah.edu

Recent reports on research supported by the Agency for Healthcare Research and Quality are summarized. These reports relate to use of aspirin for cardioprotection by patients taking NSAIDs, end of life care for nursing home residents with advanced directives, Cancer Patients' Satisfaction With Primary Care Pain Management, the need for increased medical training about adverse drug events, and dorsal root entry zone lesioning for central neuropathic pain. The research summarized in this report was abstracted from the AHRQ Research Activities.

PMID: 14640339 [PubMed - indexed for MEDLINE]

82: J Pain Palliat Care Pharmacother. 2002;16(1):81-92.

Moral lessons from the jury box.

Rich BA.

Bioethics Program, University of California at Davis Medical Center, Sacramento, CA 95817, USA. barich@ucdavis.edu

A decade ago a North Carolina jury awarded millions of dollars in damages because of a healthcare institution's failure to provide appropriate pain relief to a dying patient. In 2001, a California jury found a physician guilty of elder abuse for his failure to properly manage the pain of a cancer patient. In both instances, state licensing boards had failed to take any disciplinary action against those involved. These cases dramatically illustrate a significant and persistent gulf between the lay public and the health professions with regard to the moral significance they attach to the duty to relieve suffering. Measures to insure that all patients receive effective assessment and management of their pain must take into account this disparity, and endeavor to achieve congruence by reconnecting the health professions to their ancient and core value--the

relief of suffering.

Publication Types:

Case Reports
Legal Cases

PMID: 14650451 [PubMed - indexed for MEDLINE]

83: J Pain Palliat Care Pharmacother. 2002;16(1):61-79.

Palliative care: an international necessity.

Twycross RG.

Nuffield Department of Clinical Medicine, Oxford University, United Kingdom.
robtwy@yahoo.com

Palliative care is the care of patients whose disease is incurable and whose life expectancy is limited to weeks or months. This commentary describes the development of modern palliative care, some of the elements and underlying philosophical constructs of such care, and calls for expansion and improvement in end of life care throughout the world.

PMID: 14650450 [PubMed - indexed for MEDLINE]

84: J Pain Palliat Care Pharmacother. 2002;16(4):61-4.

Medications for patient comfort when weaning mechanical ventilation in palliative care.

Fine PG.

School of Medicine, and Pain Management Center, University of Utah Health Sciences Center, Salt Lake City, UT 84108, USA. fine@aros.net

Indications for mechanical ventilation in end of life care and the place for weaning are discussed. Preferred medications to facilitate weaning are short acting benzodiazepines. The importance of the environment in which ventilatory support is provided is discussed as are ethical issues including patient wishes and those of a patient's proxy.

PMID: 14635826 [PubMed - indexed for MEDLINE]

85: J Pain Palliat Care Pharmacother. 2002;16(3):111-2.

Hospitals and hospices improve care for chronically and terminally ill.

[No authors listed]

Publication Types:

News

PMID: 14640364 [PubMed - indexed for MEDLINE]

86: J Pain Palliat Care Pharmacother. 2002;16(3):65-71.

Defining hospice and palliative care: some further thoughts.

Lamers WM Jr.

Hospice Foundation of America, USA. lamers@earthlink.net

Widespread acceptance of hospice in the United States has contributed to increased public and professional interest in improved care, not only for dying persons, but for persons undergoing treatment for conditions that may not pose an immediate threat to their life. 'Palliative care' has been brought into use to denote care that covers a broader category of patients who do not necessarily have a medical condition that is not, at present, life threatening. The use of two related and overlapping terms by health care professionals is confusing and, in the absence of clear definitions, has contributed to needless controversy. Hospice has a specific meaning in the United States. Palliative care, once used as a euphemism for hospice, now has several meanings. This paper is designed to explore the historical evolution of both terms and to reduce the confusion and controversy surrounding their current application.

PMID: 14640357 [PubMed - indexed for MEDLINE]

87: J Pain Palliat Care Pharmacother. 2002;16(4):109-17.

The Medicare hospice benefit.

[No authors listed]

PMID: 14635834 [PubMed - indexed for MEDLINE]

88: J Pain Symptom Manage. 2003 Dec;26(6):1148-9.

An end-of-life care curriculum for nursing home staff. Improving nursing home care of the dying: a training manual for nursing home staff By Martha L. Henderson, Laura C. Hanson, and Kimberly S. Reynolds Published by Springer Publishing Company, New York, USA, 2003 216 pages, \$36.95 (softcover).

Budis JP.

James P. Budis, MSN, MPH, is a nurse practitioner in the Continuum Hospice Care/Jacob Perlow Hospice, Beth Israel Medical Center, New York, New York, USA

PMID: 14654267 [PubMed - in process]

89: J Pain Symptom Manage. 2003 Oct;26(4):897-902.

Respiratory tract secretions in the dying patient: a retrospective study.

Kass RM, Ellershaw J.

Royal Liverpool University Hospital, Liverpool, United Kingdom.

Respiratory tract secretions (RTS), the sound created by poorly-cleared mucous in the hypopharynx or bronchial tree, can be alarming for dying patients, relatives and staff. Increased knowledge into the etiology of RTS and its response to treatment is needed to improve future management. We studied retrospectively the data from 202 patients who died on a 30-bed specialist palliative care unit during a one-year period. These patients were observed every four hours during the dying phase. RTS was treated with hyoscine hydrobromide. Ninety-nine patients (49%) developed RTS. The median time from onset of RTS till death was 16 hours. Fifty-nine patients could have their treatment response assessed. Of these, 30.5% responded within four hours, 33.9% after four hours, and 35.5% died with RTS. Increasing the dose for nonresponders had no significant effect. Significant risk factors for developing RTS were found to be prolonged dying phase, primary lung cancer and male gender.

PMID: 14527758 [PubMed - indexed for MEDLINE]

90: J Palliat Med. 2003 Oct;6(5):725-36.

Factors associated with the high prevalence of short hospice stays.

Miller SC, Weitzen S, Kinzbrunner B.

Center for Gerontology and Health Care Research, Brown University Medical School, Providence, Rhode Island 02912, USA. Susan_Miller@Brown.edu

This study's goal was to gain an understanding of the factors associated with hospice stays of 7 days or less (i.e., short hospice stays), and to test the hypothesis that independent of changes in sociodemographics, diagnoses, and site-of-care, the likelihood of a short hospice stay increased over time. We examined hospice stays for 46655 nursing home and 80507 non-nursing home patients admitted between October 1994 and September 1999 to 21 hospices across 7 states, and owned by 1 provider. Logistic regression was used to determine the factors significantly associated with a higher probability of a short stay. Compared to patients admitted in (fiscal year) 1995, and controlling for potential confounders, the probability of a short stay significantly increased in each year after 1995 in nursing homes, and in 1999 in non-nursing home settings. In (fiscal year) 1995, a nursing home resident admitted to hospice had a 26% probability (95% confidence interval [CI] 0.24, 0.28) of a less than 8-day stay and, in (fiscal year) 1999, the probability was 33% (95% CI 0.31, 0.34); a non-nursing home patient had a 32% probability in 1995 (95% CI 0.30, 0.34) and a 36% probability in 1999 (95% CI 0.34, 0.37). The probability of a short hospice stay was greater for patients with noncancer diagnoses, independent of year of

hospice admission. In this paper we discuss the possible underlying reasons for the increased probability of short hospice stays and we speculate on what this increase may mean in terms of hospice's ability to provide high-quality end-of-life care.

PMID: 14622452 [PubMed - in process]

91: J Palliat Med. 2003 Oct;6(5):782-5.

Ambulatory hospice training in family medicine residency.

Stanton RN.

Family Practice, SIU Quincy Family Practice Residency, Quincy, Illinois 62301, USA. ra_naes@hotmail.com

End-of-life care has become an important competency for primary care physicians, and yet many family physicians feel unprepared in the areas of hospice and/or palliative medicine. In preparation for designing an ambulatory geriatrics rotation within a family medicine residency training program, a needs assessment revealed gaps in hospice training specific to the philosophy of hospice and the common settings in which it is practiced. A hospice-focused core curriculum unit was developed, using a community-based hospice experience and formal seminars. The resident's community-based experiences included home visits and nursing home contacts as part of a multispecialty hospice team. End-of-rotation resident assessments and rotations evaluations revealed enhanced resident understanding of hospice philosophy and venues, increased knowledge of the criteria for hospice admission and medical management of the dying patient and an increased intention to refer patients to a hospice program, although follow-up audits of referral patterns were inconclusive to date.

PMID: 14622464 [PubMed - in process]

92: J Palliat Med. 2003 Oct;6(5):809-20.

Introducing end-of-life care into the University of Cincinnati Internal Medicine Residency Program.

Warm EJ, Romer AL.

Division of General Internal Medicine, University of Cincinnati College of Medicine, Cincinnati, Ohio 45267-0535, USA. warme@uc.edu

PMID: 14622468 [PubMed - in process]

93: J Palliat Med. 2003 Oct;6(5):831-9.

Palliative care management: a Veterans Administration demonstration project.

Rosenfeld K, Rasmussen J.

The VA Greater Los Angeles Healthcare System, Los Angeles, California 90073, USA. kenneth.rosenfeld@med.va.gov

As part of a Veterans Health Administration (VA) commitment to improve end-of-life care the VA Greater Los Angeles Healthcare System (GLA) implemented Pathways of Caring, a 3-year demonstration project targeting patients with inoperable lung cancer and advanced heart failure and chronic lung disease. The program utilized case-finding for early identification of poor-prognosis patients, interdisciplinary palliative assessment, and intensive nurse care coordination to optimize symptom management, continuity and coordination of services across providers and care settings, and support for families. Program evaluation used patient and family surveys as well as reviews of medical records and administrative databases to assess processes and outcomes of care. Despite significant programmatic challenges including organizational instability and evaluation design issues, the program achieved measurable success including high rates of advance care planning, hospice enrollment, and death at home, and low end-of-life hospital and Intensive Care Unit (ICU) use. As a result of its success, the program will be expanded and its care model extended institution-wide.

PMID: 14622470 [PubMed - in process]

94: J Palliat Med. 2003 Oct;6(5):841-50.

Completing a life: development of an interactive multimedia CD-ROM for patient and family education in end-of-life care.

Ogle K, Greene DD, Winn B, Mishkin D, Bricker LG, Lambing AK.

Department of Family Practice, Michigan State University, East Lansing, Michigan 48824, USA. Karen.Ogle@ht.msu.edu

There are relatively few comprehensive and empowering educational tools to assist people with terminal illness in addressing important end-of-life issues. Identifying this scarcity, a design team of health and multimedia professionals created an interactive, educational CD-ROM entitled Completing a Life. The primary goal of the project was to provide rich content in a style that was easy to access, understand, and use. The interactive medium of the CD-ROM enabled a large amount and wide array of material to be presented in manageable segments. These segments are connected by hyperlinks, providing self-guided control over the selection, pace, and order of material. The CD puts the learning experience in the hands of the learner. The format and design is also intended to generate a sense of empowerment, at a time and around issues often associated with a loss of control. Completing a Life covers a wide range of information for the user to choose from, spanning physical, emotional, family, and spiritual issues. A calm and comforting tone and welcoming environment enhances the users' ability to take in the information and make proactive decisions about his/her own well-being and care. The CD contains video narratives of individuals who tell their own stories of living with terminal illness. In addition to being a highly relevant means of conveying sensitive, health-related information, this collection of personal interviews may offer a form of "virtual support group"

for the user. Finally, the interactive format allows stories and informational content to be linked in topic-specific ways that complement one another.

PMID: 14622471 [PubMed - in process]

95: J Palliat Med. 2003 Oct;6(5):699-705.

A high-volume specialist palliative care unit and team may reduce in-hospital end-of-life care costs.

Smith TJ, Coyne P, Cassel B, Penberthy L, Hopson A, Hager MA.

Virginia Commonwealth University Massey Cancer Center, and Medical College of Virginia Hospitals, Richmond, Virginia 23298-0230, USA. tsmith@hsu.vcu.edu

BACKGROUND: Current end-of-life hospital care can be of poor quality and high cost. High volume and/or specialist care, and standardized care with clinical practice guidelines, has improved outcomes and costs in other areas of cancer care. **METHODS:** The objective of this study was to measure the impact of the palliative care unit (PCU) on the cost of care. The PCU is a dedicated 11-bed inpatient (PCU) staffed by a high-volume specialist team using standardized care. We compared daily charges and costs of the days prior to PCU transfer to the stay in the PCU, for patients who died in the first 6 months after the PCU opened May 2000. We performed a case-control study by matching 38 PCU patients by diagnosis and age to contemporary patients who died outside the PCU cared for by other medical or surgical teams, to adjust for potential differences in the patients or goals of care. **RESULTS:** The unit admitted 237 patients from May to December 2000. Fifty-two percent had cancer followed by vascular events, immunodeficiency, or organ failure. For the 123 patients with both non-PCU and PCU days, daily charges and costs were reduced by 66% overall and 74% in "other" (medications, diagnostics, etc.) after transfer to the PCU ($p < 0.0001$ for all). Comparing the 38 contemporary control patients who died outside the PCU to similar patients who died in the PCU, daily charges were 59% lower (US dollars 5304 +/- 5850 to US dollars 2172 +/- 2250, $p = 0.005$), direct costs 56% lower (US dollars 1441 +/- 1438 to US dollars 632 +/- 690, $p = 0.004$), and total costs 57% lower (US dollars 2538 +/- 2918 to US dollars 1095 +/- 1153, $p = 0.009$). **CONCLUSIONS:** Appropriate standardized care of medically complex terminally ill patients in a high-volume, specialized unit may significantly lower cost. These results should be confirmed in a randomized study but such studies are difficult to perform.

PMID: 14622449 [PubMed - in process]

96: J Palliat Med. 2003 Oct;6(5):715-24.

Effectiveness of a home-based palliative care program for end-of-life.

Brumley RD, Enguidanos S, Cherin DA.

Home Health and Palliative Care, Southern California Permanente Medical Group, Kaiser Permanente TriCentral Service Area, Pasadena, California, USA.

CONTEXT: Despite the widespread recognition of the need for new models of care to better serve patients at the end-of-life, little evidence exists documenting the effectiveness of these models. OBJECTIVE: To evaluate the effectiveness of a palliative program for end-of-life care. DESIGN: A comparison group study was conducted between March 1999 and August 2000 comparing subjects enrolled in a palliative care intervention to those receiving usual care. SETTING: Home Health Department at Kaiser Permanente, TriCentral Service Area. SUBJECTS: During the course of the 2-year study, 558 subjects were enrolled. A subgroup of 300 patients who had died during the course of the study was selected for analysis; 161 were enrolled in the Palliative Care Program and 139 in the comparison group. INTERVENTION: The Kaiser Permanente Palliative Care Project is a multidisciplinary care management approach for home-based end of life care and treatment. The program is designed to facilitate the transition from acute to palliative care during the last 12 months of life with the goal of improving quality of life through the provision of symptom control and pain relief, emotional and spiritual support, and patient education. MAIN OUTCOME MEASURES: Medical service use and satisfaction with services. RESULTS: Palliative care patients had increased satisfaction with services at 60 days after enrollment and significantly fewer emergency department visits, hospital days, skilled nursing facility days, and physician visits than those in the comparison group. Those enrolled in palliative care averaged a 45% decrease in costs as compared to usual care patients. CONCLUSION: Through integrating palliative care into curative care practices earlier in the disease trajectory, chronically ill patients nearing the end of life report improved satisfaction with care and demonstrate less acute care use resulting in lower costs of care. In addition, patients enrolled in the palliative care program were more likely to die at home than comparison group patients.

PMID: 14622451 [PubMed - in process]

97: J Palliat Med. 2003 Oct;6(5):821-9.

Advancing End-of-Life Care: lessons learned from a statewide panel.

Brooks RG, Hardy M, Moseley R, Myrick J, Jones A.

Family Medicine and Rural Health, College of Medicine, Florida State University, Tallahassee, Florida 32306-4300, USA. robert.brooks@med.fsu.edu

The Florida Panel for the Study of End-of-Life Care was an innovative and effective approach to the formulation of end-of-life (EOL) policy recommendations that significantly influenced the legislative process and resulted in new EOL legislation. The lessons from this panel's experience are useful to other states considering legislative changes in their EOL policies. Key to the success of the EOL panel was its heterogeneous membership that allowed the collaboration of policy makers, clinicians, ethicists, citizens, and other stakeholders. Also, crucial to the success of the panel were the dimensions of the deliberative process embraced by the panel. This process supported an impressive level of mutual respect, trust, and openness among the panel members that, with only minor exceptions, allowed the members of the panel to rise above the parochial political battles that have often preempted serious debate on controversial EOL issues. The recommendations of the EOL panel led to

new state laws on EOL care and improvements in public awareness, professional education, and clinical protocols for implementing patients' wishes. Another major but largely unforeseen consequence of the EOL panel was the development of significant new working alliances among members and organizations. These alliances led to new projects on EOL care and have significantly improved communication and working relationships between organizations and individuals committed to improving EOL care.

PMID: 14622469 [PubMed - in process]

98: J Palliat Med. 2003 Aug;6(4):605-13.

Competency in end-of-life care: last hours of life.

Ferris FD, von Gunten CF, Emanuel LL.

Palliative Care Standards/Outcome Measures, San Diego Hospice and Palliative Care, 4311 Third Avenue, San Diego, CA 92103-1407, USA. fferris@sdhospice.com

Clinical competence, willingness to educate, and calm and empathic reassurance are critical to helping patients and families in the last hours of living. This review adapted from the Education for Physicians on End-of-Life Care (EPEC) Curriculum describes the predictable course that occurs as well as approaches to management. Management principles are the same at home or in a health care institution. However, death in an institution requires accommodations to assure privacy, cultural observances, and communication that may not be customary. In anticipation of the event, it helps to inform the family and other professionals about what to do and what to expect. Care does not end until the family has been supported with their grief reactions and those with complicated grief helped to get care. Care at the end of life is a core competency.

Publication Types:

Review

Review, Tutorial

PMID: 14516502 [PubMed - indexed for MEDLINE]

99: J Palliat Med. 2003 Aug;6(4):585-91.

Charity for the dying: who receives unreimbursed hospice care?

Lorenz KA, Rosenfeld KE, Asch SM, Ettner SL.

VA Greater Los Angeles Healthcare System, Veterans Integrated Palliative Program, Division of General Internal Medicine, 11301 Wilshire Boulevard, Code 111-G, Los Angeles, CA 90073, USA. karl.lorenz@med.va.gov

OBJECTIVES: Many deaths occur among persons without insurance coverage for hospice care. We examined the patient and agency characteristics associated with receiving unreimbursed hospice care in a national survey. RESULTS: We examined the receipt of unreimbursed care using the 1998 National Home and Hospice Care

Survey (NHHCS) discharge dataset. Overall, only 3% of hospice patients received unreimbursed care. Because 98% of older adults are eligible for Medicare, we stratified multivariate analysis on age greater or less than 65 years. Among persons less than 65 years of age, younger, nonwhite persons were more likely to receive unreimbursed care, as were persons with cancer. Agencies providing unreimbursed care to persons over the age of 65 years were more likely to be not-for-profit and freestanding. CONCLUSION: Recipients of unreimbursed hospice care are demographically similar to the uninsured, and whether uninsured persons receive unreimbursed hospice care depends on clinical and agency organizational factors related to the motivation to provide unreimbursed care.

PMID: 14516500 [PubMed - indexed for MEDLINE]

100: J Palliat Med. 2003 Aug;6(4):575-84.

Validation of a new measure of concept of a good death.

Schwartz CE, Mazor K, Rogers J, Ma Y, Reed G.

Division of Preventive and Behavioral Medicine, Department of Medicine,
University of Massachusetts Medical School, Worcester, MA, USA.
carolyn.schwartz@deltaquest.org

BACKGROUND: The concept of a good death is central to end-of-life care research. Despite its importance and the high interest in the topic, there are few measures currently available for use in clinical research. **PURPOSE:** The present work describes the development and testing of a set of items intended to measure the importance of several components posited to be critical to the concept of a good death. It is intended for use with health care providers and lay people in the context of end-of-life care research and education. **POPULATION:** Four cohorts (n = 596) were recruited to participate, representing two helping profession disciplines, nonhelping professionals, and a range of ages, specifically: (1) undergraduate medical students; (2) master's degree students in nursing; (3) graduate students from the life sciences; and (4) practicing hospice nurses. **METHODS:** Participants completed self-report questionnaires at baseline and retest. Psychometric analyses included item frequency distributions, factor analysis, alpha reliability, intraclass correlation, and measures of association. **RESULTS:** The new Concept of a Good Death measure demonstrated good item frequency distributions, acceptable internal consistency reliability, and test-retest stability. Its factor structure revealed that three distinct domains are measured, reflecting the psychosocial/spiritual, physical, and clinical aspects of a good death. An examination of patterns of correlations showed differential associations with death anxiety, spiritual beliefs and practices, anxious mood, and sociodemographic characteristics. **CONCLUSIONS:** The new Concept of a Good Death instrument appears to measure three distinct factors which people consider important to a Good Death. Ratings of the importance of these factors are reliable and valid. The instrument has the advantage of being a brief, self-report index for use in end-of-life care research.

PMID: 14516499 [PubMed - indexed for MEDLINE]

101: J Palliat Med. 2003 Aug;6(4):543-56.

A palliative care needs assessment of health care institutions in Wisconsin.

Greiner L, Buhr B, Phelps D, Ward S; Wisconsin Coalition To Improve Palliative Care.

Department of Radiology, Angio/Interventional Section, University of Wisconsin Hospital and Clinics, Madison, WI 53792, USA.

BACKGROUND: In 1999 the Wisconsin Coalition to Improve Palliative Care (WCIPC) conducted a palliative care needs assessment of health care institutions throughout the state of Wisconsin to document the current status of palliative care and identify institutional barriers and opportunities for improvement. **METHOD:** A survey instrument was developed to assess provisions of palliative care in the following areas: services currently provided, staff education programs offered in the previous year, barriers to the delivery of palliative care, and resources that would be useful to the participating institutions. Surveys were mailed to 881 health care institutions in Wisconsin; 318 (36%) surveys were returned. **RESULTS:** The three most common end-of-life care services present included a program to promote advance care planning, a contractual relationship with one or more hospice programs, and an interdisciplinary care program for dying patients. Pain management and advance directives were the two most common topics of educational programs offered in the past year. The most frequently cited barriers to good end-of-life care included a lack of knowledge among patients/families, a lack of provider knowledge about pain and symptom control, and poor reimbursement for end-of-life care. Resources that institutions felt would be useful included newsletters, a speaker's bureau, and information about establishing quality improvement programs for palliative care. **CONCLUSIONS:** While health care institutions in Wisconsin provide a variety of palliative care services and offer educational programs that address areas of palliative care, institutional barriers do exist. This needs assessment provides valuable descriptive data that will guide efforts to improve palliative care throughout the state of Wisconsin.

PMID: 14516496 [PubMed - indexed for MEDLINE]

102: J Palliat Med. 2003 Aug;6(4):623-4.

The extreme importance of insignificance.

Wright LD.

Hospice of Muskegon-Oceana, 1050 West Western Avenue, Muskegon, MI 49441, USA.

PMID: 14516506 [PubMed - indexed for MEDLINE]

103: J Palliat Med. 2003 Aug;6(4):641-4.

Adding hospice and palliative care services to the cancer center menu.

Smith T.

Publication Types:
Editorial

PMID: 14516510 [PubMed - indexed for MEDLINE]

104: J Palliat Med. 2003 Aug;6(4):661-9.

"Do It Your Way": a demonstration project on end-of-life care for persons with serious mental illness.

Foti ME.

Department of Psychiatry, University of Massachusetts Medical School, Worcester, MA, USA. maryellen.foti@dmh.state.ma.us

Over the last decade, America's health care systems have been challenged to incorporate advance care planning and end-of-life care into their service delivery systems to assure that persons with terminal illnesses receive compassionate individualized care. Despite the surge in new research and knowledge, some groups remain understudied and underserved, such as persons with serious mental illness. "Do It Your Way," a demonstration project, was developed and implemented in a Massachusetts public mental health system to improve access to advance care planning and end-of-life care among persons with serious mental illness. This report provides an overview of the project, including its rationale, setting, needs assessment, objectives, initiatives, preliminary evaluation, impact, and conclusions.

Publication Types:
Review
Review, Tutorial

PMID: 14516513 [PubMed - indexed for MEDLINE]

105: J Palliat Med. 2003 Aug;6(4):671-83.

CHOICES: promoting early access to end-of-life care through home-based transition management.

Stuart B, D'Onofrio CN, Boatman S, Feigelman G.

Sutter Visiting Nurse Association and Hospice, 1900 Powell Street, Suite 300, Emeryville, CA 94608, USA. stuartb@sutterhealth.org

CHOICES is a comprehensive home-based care coordination program designed to bridge the gap between home health and hospice for Medicare + Choice enrollees

with advanced chronic illness in San Francisco's East Bay region. Key elements of the program include physician education, enrollment of patients with high disease burden who may not be terminally ill, co-management of care with the primary physician, and an advanced practice clinical team that provides comprehensive in-home assessments, a flexible mix of life-prolonging and palliative care that evolves with disease progression, focused education and advance planning, and caregiver support. During a 42-month demonstration, 208 patients were enrolled in the program. Eighty percent had a non-cancer diagnosis; 40% were people of color. After an 8-month follow-up, 44% of the study cohort had died in the program or after transfer to hospice, 51% had been discharged, and 5% remained active. Median length of stay for decedents was 260 days. Preliminary evidence supports the program's feasibility and acceptability to patients, families, physicians, and agency partners. However, the uncertain future of Medicare + Choice and of managed care may jeopardize the program's sustainability. Policymakers and taxpayers will need to determine how to care for the growing number of chronically ill elderly who wish to remain at home as illness advances. The care needs of these patients and their families may overwhelm a health system organized around hospital treatment of acute illness.

PMID: 14516514 [PubMed - indexed for MEDLINE]

106: J Prof Nurs. 2003 Nov-Dec;19(6):372-81.

Analysis of end-of-life content in critical care nursing textbooks.

Kirchhoff KT, Beckstrand RL, Anumandla PR.

Nurses have identified a need for improving their knowledge and skills in providing end-of-life care. Critical care nursing textbooks can serve as an important source of information on end-of-life care for critical care nurses. Hence, an analysis of end-of-life content in 14 critical care nursing textbooks was conducted. Critical care nursing textbooks used for review were published in 1995 or later and identified from the libraries at the University of Wisconsin-Madison and Brigham Young University. The end-of-life content areas identified by the American Association of Colleges of Nursing (AACN), under which the AACN end-of-life competencies for undergraduate nursing students can be taught, were used as a framework for assessing the presence or absence of end-of-life content in the textbooks. When end-of-life content was present, two reviewers judged whether the information was helpful. Four additional end-of-life content areas were identified in some textbooks during the study, and reviewers also judged whether these were helpful. None of the textbooks had end-of-life content in all the content areas used for the analysis. Three textbooks did not contain any end-of-life content.

PMID: 14689394 [PubMed - in process]

107: JAMA. 2004 Jan 7;291(1):88-93.

Family perspectives on end-of-life care at the last place of care.

Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V.

Center for Gerontology and Health Care Research, Brown Medical School,
Providence, RI, USA. joan_teno@brown.edu

CONTEXT: Over the past century, nursing homes and hospitals increasingly have become the site of death, yet no national studies have examined the adequacy or quality of end-of-life care in institutional settings compared with deaths at home. OBJECTIVE: To evaluate the US dying experience at home and in institutional settings. DESIGN, SETTING, AND PARTICIPANTS: Mortality follow-back survey of family members or other knowledgeable informants representing 1578 decedents, with a 2-stage probability sample used to estimate end-of-life care outcomes for 1.97 million deaths from chronic illness in the United States in 2000. Informants were asked via telephone about the patient's experience at the last place of care at which the patient spent more than 48 hours. MAIN OUTCOME MEASURES: Patient- and family-centered end-of-life care outcomes, including whether health care workers (1) provided the desired physical comfort and emotional support to the dying person, (2) supported shared decision making, (3) treated the dying person with respect, (4) attended to the emotional needs of the family, and (5) provided coordinated care. RESULTS: For 1059 of 1578 decedents (67.1%), the last place of care was an institution. Of 519 (32.9%) patients dying at home represented by this sample, 198 (38.2%) did not receive nursing services; 65 (12.5%) had home nursing services, and 256 (49.3%) had home hospice services. About one quarter of all patients with pain or dyspnea did not receive adequate treatment, and one quarter reported concerns with physician communication. More than one third of respondents cared for by a home health agency, nursing home, or hospital reported insufficient emotional support for the patient and/or 1 or more concerns with family emotional support, compared with about one fifth of those receiving home hospice services. Nursing home residents were less likely than those cared for in a hospital or by home hospice services to always have been treated with respect at the end of life (68.2% vs 79.6% and 96.2%, respectively). Family members of patients receiving hospice services were more satisfied with overall quality of care: 70.7% rated care as "excellent" compared with less than 50% of those dying in an institutional setting or with home health services ($P < .001$). CONCLUSIONS: Many people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and being treated with respect. Family members of decedents who received care at home with hospice services were more likely to report a favorable dying experience.

PMID: 14709580 [PubMed - in process]

108: JAMA. 2003 Dec 10;290(22):2939; author reply 2939-40.

Comment on:

JAMA. 2003 Aug 13;290(6):790-7.

End-of-life practices in European intensive care units.

Giannini A.

Publication Types:

Comment

Letter

PMID: 14665650 [PubMed - indexed for MEDLINE]

109: JAMA. 2003 Dec 10;290(22):2938-9; author reply 2939-40.

Comment on:

JAMA. 2003 Aug 13;290(6):790-7.

End-of-life practices in European intensive care units.

Kompanje EJ.

Publication Types:

Comment

Letter

PMID: 14665649 [PubMed - indexed for MEDLINE]

110: JAMA. 2003 Nov 26;290(20):2721-9.

A 62-year-old woman with chronic obstructive pulmonary disease.

Celli BR.

Tufts University, USA. bcelli@copdnet.org

Publication Types:

Case Reports

Clinical Conference

PMID: 14645315 [PubMed - indexed for MEDLINE]

111: JAMA. 2003 Nov 12;290(18):2379-80.

A piece of my mind. Grams.

Dean C.

PMID: 14612460 [PubMed - indexed for MEDLINE]

112: Lancet. 2003 Oct 18;362(9392):1313.

Sources of error: from procedures to end-of-life decisions.

Duke T.

Department of Paediatrics, Royal Children's Hospital, Victoria 3052, Parkville, Australia.

Publication Types:
Case Reports

PMID: 14575978 [PubMed - indexed for MEDLINE]

113: Leg Med (Tokyo). 2003 Mar;5 Suppl 1:S20-8.

Active euthanasia and physician-assisted suicide: the German discussion.

Oehmichen M, Meissner C.

Institute of Forensic Medicine, University Hospital of Kiel,
Arnold-Heller-Strasse 12, D-24105 Kiel, Germany.
oehmich@rechtsmedizin.uni-kiel.de

The debate on legalization of active euthanasia in the Netherlands and Belgium and the refused legal right to choose the circumstances of Diana Pretty's own death are the last actual reasons for reconsidering the situation in Germany. Around the world heated debates have broken out on the topic of active euthanasia. Specialists in the field of 'forensic medicine' have taken full part in these discussions. The present survey from the point of view of forensic medicine begins with a look at current terminology and at the laws pertaining to euthanasia in Germany. These laws are then contrasted with actual practice, including a description of the increasing acceptance of active euthanasia by the German population. The main argument against legalization of active euthanasia is that its formal acceptance in law would cause the dam of restraint to burst, culminating in widespread misuse, as already seen in recent serial killings by nurses in hospitals and homes for the elderly around the world. Contrasted with this are the arguments for taking active steps at the end of life, including emotional considerations such as the revulsion against mechanized medicine and the fear of pain and rational arguments such as the necessity to end a 'life unworthy of life', to save medical costs, and obtaining prior consent in 'living wills'. Such considerations have put in jeopardy the moral integrity of the medical profession - and thus the layperson's trust in physicians--around the world. In Germany especially the history of mass killing during the Nazi era constitutes a fundamental argument against active euthanasia. As a consequence, in Germany active euthanasia will not receive legal sanction, although recommendations on rendering dying more bearable are permitted.

Publication Types:
Review
Review, Tutorial

PMID: 12935547 [PubMed - indexed for MEDLINE]

114: Leg Med (Tokyo). 2003 Mar;5 Suppl 1:S60-4.

Euthanasia in the Netherlands: 25 years of experience.

Dupuis HM.

Department of Metamedica, Leiden University Medical School, P.O. Box 2087, NL 2301, CB Leiden, The Netherlands. h.m.dupuis@lumc.nl

This article gives an impression of the experience with legal euthanasia practices in the Netherlands for approximately 25 years. Some figures are presented about the medical presence at the end of life. Also the legal and moral aspects of euthanasia are addressed. The article starts with a description of the background of the debate on euthanasia and gives some conditions for a really open and serious debate in a society on this subject.

Publication Types:

Review

Review, Tutorial

PMID: 12935553 [PubMed - indexed for MEDLINE]

115: Mayo Clin Proc. 2003 Nov;78(11):1397-401.

Use of opioids in the treatment of severe pain in terminally ill patients--dying should not be painful.

Moynihan TJ.

Division of Medical Oncology, Mayo Clinic, Rochester, Minn 55905, USA.
moynihan.timothy@mayo.edu

Pain is a common symptom at the end of life. The vast majority of pain can be readily managed if simple principles of practice are followed. Chronic pain requires continuous analgesia, and severe pain requires use of strong analgesics, most commonly the opioids. In addition to drugs administered continually, short-acting medications must be available for "breakthrough" pain. This article reviews the principles of pain management in terminally ill patients, using a case-based demonstration.

Publication Types:

Case Reports

Review

Review, Tutorial

PMID: 14601699 [PubMed - indexed for MEDLINE]

116: Med Health Care Philos. 2003;6(3):263-72.

Moral problems in palliative care practice: a qualitative study.

Hermsen MA, ten Have HA.

University Medical Centre Nijmegen, Department of Ethics, Philosophy and History

Library Program Office
Office of Information
Veterans Health Administration

of Medicine, 232 EFG, PO Box 9101, 6500 HB Nijmegen, the Netherlands.
M.Hermesen@efg.umcn.nl

Clarifying and analysing moral problems arising in the practice of palliative care was the objective of participatory observations in five palliative care settings. The results of these observations will be described in this contribution. The moral problems palliative caregivers have to deal with in their daily routines will be explained by comparison with the findings of a previously performed literature study. The specific differences in the manifestation of moral problems in the different palliative care settings will be highlighted as well.

Publication Types:
Review
Review, Tutorial

PMID: 14620463 [PubMed - indexed for MEDLINE]

117: Med Law. 2003;22(3):551-60.

Doctors can kill--active euthanasia in South Africa.

Oosthuizen H.

Department of Criminal and Medical Law, University of the Free State,
Bloemfontein, South Africa.

Medical practitioners in South Africa will be given the legal right to end the lives of terminally ill patients. This is the practice of active euthanasia, the procedure whereby a medical doctor or a professional nurse can end the life of a terminally ill patient at the patient's request, by providing or administering a lethal dosage of a drug. Voluntary active euthanasia is included in a Draft Bill--The End of Life Decisions Act--which form part of a report of the South African Law Commission, wherein regulations regarding the end-of-life decisions are formulated. Specifically, it provides that a medical practitioner may under certain conditions stop the treatment of a patient whose life functions are being maintained artificially. Further, that a competent person may refuse life-sustaining treatment if he chooses to die. A medical practitioner may also give effect to a patient's living will in which the patient has requested the cessation of treatment. The Act also provides for the options of active voluntary euthanasia or physician-assisted suicide.

PMID: 14626887 [PubMed - indexed for MEDLINE]

118: Med Law. 2003;22(3):543-50.

The Dutch model for legalizing end-of-life decisions.

Kater L.

School of Business, Public Administration and Technology, University of Twente,

Enschede, The Netherlands.

The Dutch experience with euthanasia is used as a model for other countries for regulating end-of-life decisions. Several elements of the Dutch debate, for example the definition of euthanasia, are copied and imported to other debates. This paper studies the specific Dutch construction of regulating euthanasia and the concept of the requirements of prudent practice. The requirements of prudent practice embody the conditions for careful medical management in end-of-life decisions. It is argued that the requirements of prudent practice are a relatively acceptable way of regulating the Dutch practice of euthanasia as they are embedded in an elaborate network of relations, standards and values. As a consequence of this local character and the way the requirements of prudent practice relate to the Dutch practice of euthanasia it is difficult to simply transport them to other countries in order to regulate euthanasia.

PMID: 14626886 [PubMed - indexed for MEDLINE]

119: Med Law. 2003;22(3):533-42.

Decision-making at the end-of-life and the incompetent patient: a comparative approach.

Halliday S, Witteck L.

Institute of Medicine, Law & Bioethics, Liverpool Law School, University of Liverpool, United Kingdom.

In contrast to the situation in the Netherlands and Belgium, the legislatures in both England & Wales and Germany have not recognised that active euthanasia may be lawful in any circumstance. Nevertheless, the courts in both jurisdictions have held that passive euthanasia, that is the withdrawal or withholding of life-prolonging treatment, is perfectly lawful; indeed it will often constitute good medical practice. This article adopts a comparative approach to assessing the manner in which decisions to withdraw or withhold life-prolonging treatment are made in relation to previously competent patients without a legally effective advance directive or a proxy decision-maker, considering the approaches adopted by the courts in England & Wales and Germany: the best interests and 'presumed will' approaches respectively. Due to the inherent drawbacks associated with each approach it is concluded that the best way forward would be for both jurisdictions to adopt a mixed approach, allowing the autonomy model to temper the best interests approach, recognising that the patient is an individual rather than simply an object of concern.

Publication Types:
Legal Cases

PMID: 14626885 [PubMed - indexed for MEDLINE]

120: Med Sci Monit. 2003 Sep;9(9):ET21-7.

What the clinician taught the ethicist: clinical contributions to ethical

concerns.

Koch T.

Department of Geography, University of British Columbia, Vancouver, BC, Canada.
tokoch@attglobal.net

BACKGROUND: Clinical ethics is often assumed to be a one-way relationship in which ethicists consider the appropriate guidelines for clinical practice and research. This unfortunately ignores the important ways clinical practice informs bioethical thinking. **MATERIAL/METHODS:** This paper considers the relation between clinical and ethical practice through a consideration of whether there are conditions in which Physician Assisted Suicide, or other forms of euthanasia, serve as an ethically accepted response to chronic illness. At one scale it reviews publicly available data on deaths attributed to euthanasia practitioner Jack Kevorkian to consider the medical rationale of those deaths. At another scale, the 'mercy killing' by Canadian farmer Robert Latimer of his daughter is employed as a case study of surrogate decision making. **RESULTS:** A clinical review of the more than seventy cases attributed to Jack Kevorkian from 1990-98 reveals a client base that did not fit publicly or clinically accepted parameters within which euthanasia is generally understood. Few if any of the patients were near the end stage of a chronic progressive disease. Most were able to travel independently. Palliative care was in some cases problematic. The case of Latimer emphasizes the importance of social as well as medical care in cases of chronic illness, and the importance of palliative care as an alternative to **CONCLUSIONS:** Clinical ethics is of necessity a two-way street, one in which ethical paradigms influence practitioners and researchers whose expertise, in turn, necessarily educates the non-clinical ethicist.

PMID: 12960919 [PubMed - indexed for MEDLINE]

121: Mont Law Rev. 1998 Summer;59(2):301-41.

The last best place to die: physician-assisted suicide and Montana's constitutional right to personal autonomy privacy.

Fisk SA.

PMID: 14631926 [PubMed - indexed for MEDLINE]

122: N Engl J Med. 2004 Jan 1;350(1):7-8.

Advance care planning.

Gillick MR.

Harvard Vanguard Medical Associates and the Department of Ambulatory Care and Prevention, Harvard Medical School, Boston, USA.

PMID: 14702421 [PubMed - indexed for MEDLINE]

123: N Engl J Med. 2003 Dec 25;349(26):2565-7; author reply 2565-7.

Comment on:

N Engl J Med. 2003 Sep 18;349(12):1109-10.

Withdrawal of mechanical ventilation.

Appleton M.

Publication Types:

Comment

Letter

PMID: 14699649 [PubMed - indexed for MEDLINE]

124: N Engl J Med. 2003 Nov 13;349(20):1891-2.

Comment on:

N Engl J Med. 2003 Nov 13;349(20):1936-42.

Costs to society of family caregiving for patients with end-stage Alzheimer's disease.

Prigerson HG.

Department of Psychiatry, Yale University, New Haven, Conn, USA.

Publication Types:

Comment

PMID: 14614164 [PubMed - indexed for MEDLINE]

125: N Engl J Med. 2003 Nov 13;349(20):1936-42.

Comment in:

N Engl J Med. 2003 Nov 13;349(20):1891-2.

End-of-life care and the effects of bereavement on family caregivers of persons with dementia.

Schulz R, Mendelsohn AB, Haley WE, Mahoney D, Allen RS, Zhang S, Thompson L, Belle SH; Resources for Enhancing Alzheimer's Caregiver Health Investigators.

Department of Psychiatry, University of Pittsburgh, Pittsburgh, USA.

schulz@pitt.edu

BACKGROUND: Although family caregiving has been intensively studied in the past decade, little attention has been paid to the impact of end-of-life care on caregivers who are family members of persons with dementia or to the caregivers'

responses to the death of the patient. METHODS: Using standardized assessment instruments and structured questions, we assessed the type and intensity of care provided by 217 family caregivers to persons with dementia during the year before the patient's death and assessed the caregivers' responses to the death. RESULTS: Half the caregivers reported spending at least 46 hours per week assisting patients with activities of daily living and instrumental activities of daily living. More than half the caregivers reported that they felt they were "on duty" 24 hours a day, that the patient had frequent pain, and that they had had to end or reduce employment owing to the demands of caregiving. Caregivers exhibited high levels of depressive symptoms while providing care to the relative with dementia, but they showed remarkable resilience after the death. Within three months of the death, caregivers had clinically significant declines in the level of depressive symptoms, and within one year the levels of symptoms were substantially lower than levels reported while they were acting as caregivers. Seventy-two percent of caregivers reported that the death was a relief to them, and more than 90 percent reported belief that it was a relief to the patient. CONCLUSIONS: End-of-life care for patients with dementia was extremely demanding of family caregivers. Intervention and support services were needed most before the patient's death. When death was preceded by a protracted and stressful period of caregiving, caregivers reported considerable relief at the death itself. Copyright 2003 Massachusetts Medical Society

Publication Types:

Clinical Trial
Multicenter Study
Randomized Controlled Trial

PMID: 14614169 [PubMed - indexed for MEDLINE]

126: Nephrol Dial Transplant. 2003 Aug;18(8):1644-7.

Haemodialysis patients' views on their resuscitation status.

Ostermann ME, Nelson SR.

Department of Renal Medicine & Transplantation, St George's Hospital, London, UK. marlies@ostermann.freemove.co.uk

BACKGROUND: Guidelines on cardiopulmonary resuscitation (CPR) recommend that decisions about resuscitation are part of every patient's care plan. We aimed to ascertain the initial views of a haemodialysis cohort in the UK regarding their CPR status in the event of an in-hospital cardiac arrest not related to dialysis. METHODS: During outpatient clinic follow-up between January and March 2001, 66 haemodialysis patients were interviewed by one of two interviewers. A standard interview format was used, which included information on complications and outcome of CPR in haemodialysis patients. Patients had no prior opportunity to discuss the issue with a third party. RESULTS: Fifty patients (76%) wished to receive CPR. Five patients decided against CPR, of whom two were depressed. Six patients were undecided. Five patients were excluded from the analysis because of lack of mental capacity or language difficulties. Patients who wished to receive CPR were significantly younger (59 +/- 16 vs 74 +/- 10 years, respectively; P < 0.01) and had a significantly higher serum albumin level compared with those who did not opt for CPR or were undecided. There was no

difference in gender, comorbidity, length of time on dialysis, proportion of patients with adequate dialysis and mean haemoglobin level between those who wished CPR and those who did not. CONCLUSIONS: The majority of haemodialysis patients wished to receive CPR. These patients were younger than those who did not opt for CPR. Clearer strategies on third-party consultation and follow-up interviews are needed to guarantee that patients' wishes are respected at all times.

PMID: 12897107 [PubMed - indexed for MEDLINE]

127: Nephrol News Issues. 2003 Sep;17(10):32-4.

From here to eternity. How do physicians learn to let go? Part 2. Parting gifts what begins when technology ends.

Bartlow B.

PMID: 14533514 [PubMed - indexed for MEDLINE]

128: North Carol Law Rev. 1998 Jan;76(2):353-406.

Hospital ethics committees as the forum of last resort: an idea whose time has not come.

Wilson RF.

Mayor, Day, Caldwell & Keeton, L.L.P., Houston, Texas, USA.

PMID: 14631927 [PubMed - indexed for MEDLINE]

129: Nurs Crit Care. 2003 Sep-Oct;8(5):209-11.

Monitoring the dying patient in ITU: a personalized discussion.

Ramsay AM.

Norfolk & Norwich University NHS Trust Colney Lane, Norwich.
AnneMarieMunro@aol.com

PMID: 14653528 [PubMed - indexed for MEDLINE]

130: Nurs Educ Perspect. 2003 Jul-Aug;24(4):176-83.

Communication skills for end-of-life nursing care. Teaching strategies from the ELNEC curriculum.

Matzo ML, Sherman DW, Sheehan DC, Ferrell BR, Penn B.

New Hampshire Community Technical College, Manchester, USA.

The End of Life Nursing Education Consortium (ELNEC) is a train-the-trainer educational program that helps nursing faculty integrate care of the dying patient and the patient's family into the nursing curriculum. This article presents pedagogical techniques derived from the ELNEC teaching module on communication and key content areas for developing communication skills in end-of-life care. Competent end-of-life nursing care begins with an understanding of communication techniques and their potential impact on care.

PMID: 14528862 [PubMed - indexed for MEDLINE]

131: Nurs Hist Rev. 2004;12:25-46.

Home hospice versus home health: cooperation, competition, and cooptation.

Buck J.

University of Virginia, USA.

Publication Types:
Historical Article

PMID: 14608846 [PubMed - indexed for MEDLINE]

132: Nurs Manage. 2003 Nov;34(11):36-9.

Telehospice carries end-of-life care over the lines.

Whitten P, Doolittle G, Mackert M, Rush T.

Telecommunications Department, Michigan State University, USA.

Outline the positive and negative predictors of telehospice use, namely its impact on organizational and management issues.

PMID: 14671449 [PubMed - in process]

133: Nurs Stand. 2003 Nov 12-18;18(9):13.

Right up to the end.

Parish C.

PMID: 14649186 [PubMed - indexed for MEDLINE]

134: Nurs Times. 2003 Sep 30-Oct 6;99(39):56-7.

Oncology is where caring really counts.

Smy J.

PMID: 14562667 [PubMed - indexed for MEDLINE]

135: Nurs Times. 2003 Sep 30-Oct 6;99(39):26-9.

A bereavement care service to address multicultural user needs.

Chaplin D.

University Hospital Birmingham NHS Trust, Birmingham.

A bereavement care service was set up in a large, acute NHS trust to understand and address the multicultural and multifaith needs of all its users. The service has not only facilitated support and guidance for friends and relatives at a time of great need and vulnerability, it has also made professionals throughout the trust aware of the importance of death with dignity.

PMID: 14562658 [PubMed - indexed for MEDLINE]

136: Nurse Educ. 2003 Nov-Dec;28(6):266-70.

The end-of-life nursing education consortium (ELNEC) experience.

Matzo ML, Sherman DW, Penn B, Ferrell BR.

Union institute and University, Cincinnati, Ohio, USA. mmatzo@tui.edu

The End-of-Life Nursing Education Consortium (ELNEC) is a train-the-trainer educational program to help nursing faculty integrate care of the dying patient and the patient's family in the nursing curriculum. The authors describe the ELNEC experience, which prepares nurse educators to competently teach end-of-life care, and provides them with the necessary knowledge, skills, and resources to effectively integrate end-of-life content into existing nursing curricula.

PMID: 14624125 [PubMed - in process]

137: Nurse Pract. 2003 Oct;28(10):6; discussion 6.

Differences in hospice referrals.

VanAlstine N.

Publication Types:

Letter

PMID: 14560124 [PubMed - indexed for MEDLINE]

138: NY Times (Print). 2003 Oct 26;;A18.

In feeding-tube case, many neurologists back courts.

McNeil DG.

Publication Types:
Newspaper Article

PMID: 14610772 [PubMed - indexed for MEDLINE]

139: NY Times (Print). 2003 Oct 16;;A14.

Feeding tube is removed in Florida right-to-die case: governor says he will try to stop death.

Goodnough A.

Publication Types:
Newspaper Article

PMID: 14610770 [PubMed - indexed for MEDLINE]

140: Oncol Nurs Forum. 2003 Nov-Dec;30(6):1022-8.

The role of the family in treatment decision making by patients with cancer.

Zhang AY, Siminoff LA.

Case Western Reserve University, Cleveland, OH, USA. axz16@po.cwru.edu

PURPOSE/OBJECTIVES: To examine family disagreements about treatment decisions for patients with advanced lung cancer. **RESEARCH APPROACH:** Descriptive, qualitative study. **SETTING:** A large comprehensive cancer center in Cleveland, OH. **PARTICIPANTS:** 37 patients with stage III or IV lung cancer and 40 caregivers (24 primary and 16 secondary) from 26 families were interviewed. **METHODOLOGIC APPROACH:** Open-ended audiotaped interviews were transcribed verbatim. **NUD*IST** (non-numerical unstructured data indexing, searching, and theorizing) computer software (QSR International, Melbourne, Australia) was used to perform content analysis. **MAIN RESEARCH VARIABLES:** Vast differences in opinions between patients and family caregivers about treatment decisions and care. **FINDINGS:** Sixty-five percent of families reported various family disagreements that mainly concerned routine treatment decisions, discontinuation of therapeutic treatment, and use of hospice care. **CONCLUSIONS:** Family disagreements about treatment decisions for patients with advanced lung cancer are common and include a wide range of

issues. Family members play an important role in the selection of patients' doctors, hospitals, treatment options, and provisions of care. INTERPRETATION: The findings suggest that nurses need to be aware of differences of opinion between patients with advanced cancer and their caregivers. Knowledge of family disagreements about treatment decisions can help nurses' efforts to integrate families into decision-making processes in clinical settings to facilitate family communications and improve patients' and caregivers' satisfaction with treatment decisions.

PMID: 14603359 [PubMed - indexed for MEDLINE]

141: *Oncol Nurs Forum*. 2003 Sep-Oct;30(5):E100-5.

Online exclusive: family satisfaction with perception of and barriers to terminal care in Japan.

Ogasawara C, Kume Y, Andou M.

Department of Nursing, School of Allied Health Science, Osaka University, Osaka, Japan. ogasawar@sahs.med.osaka-u.ac.jp

PURPOSE/OBJECTIVES: To examine how families of patients with cancer perceive and are satisfied with terminal care given in a university hospital and to identify barriers to the best care for patients and proper support for their families. **DESIGN:** Quantitative, descriptive. **SETTING:** A Japanese national university hospital. **SAMPLE:** Convenience sample of 73 family members of deceased patients with cancer (response rate was 55%). **METHODS:** Completion of a questionnaire comprised of 23 items, including multiple-choice and open-ended questions. **MAIN RESEARCH VARIABLES:** Satisfaction with terminal care, misunderstanding of narcotics use, recognition of disease signs and symptoms, and expectations for terminal care. **FINDINGS:** Ninety percent of respondents were satisfied with nursing care. Eighty percent were satisfied with the information they received at admission, 70% were satisfied at the critical phase, and 63% were satisfied at the end of life. The main expected types of desirable terminal care were pain management and spiritual care. The bereaved had difficulty dealing with patients' pain, dyspnea, and appetite loss. Forty-four patients were treated with narcotics. Fifty-seven percent of the family members of these patients found pain to be the most difficult symptom to deal with. Fifty-eight percent of the respondents believed that if narcotics were used, patients would soon die. **CONCLUSIONS:** Terminal cancer care given in Japanese university hospitals does not appear to be adequate in terms of patients' and families' quality of life. The findings indicate that insufficient current information is given throughout the terminal stage of cancer and patients and their families misunderstand the use of narcotics. **IMPLICATIONS FOR NURSING:** Oncology nurses need to consider different cultural backgrounds when offering specific care to patients with terminal cancer. Patients and their families must be educated about the efficacy of narcotics in the care of terminally ill patients with cancer.

PMID: 12949603 [PubMed - indexed for MEDLINE]

142: ONS News. 2003 Nov;18(11):1, 4-5.

Enhancing end-of-life: oncology nurses can be effective change agents.

Biedrzycki BA.

School of Medicine, Johns Hopkins University in Baltimore, MD, USA.

PMID: 14635339 [PubMed - indexed for MEDLINE]

143: ONS News. 2003 Oct;18(10):1, 4-6.

Models of palliative care: moving beyond hospice.

Rutledge DN.

Department of Nursing, California State University at Fullerton, USA.

PMID: 14608718 [PubMed - indexed for MEDLINE]

144: Pain Med. 2003 Sep;4(3):269-76.

Methadone and the hospice patient: prescribing trends in the home-care setting.

Weschules DJ, McMath JA, Gallagher R, Alt CJ, Knowlton CH.

Excellerx Institute, Philadelphia, Pennsylvania 19106, USA.
dweschules@excellerx.com

OBJECTIVE: To identify frequency and utilization patterns of methadone by hospice patients in the home-care setting. **PATIENTS AND SETTING:** All hospice patients admitted to a North American palliative care specialty pharmacy and dispensed methadone from November 1, 2001 to October 31, 2002 were analyzed.

We

also analyzed all hospice patients dispensed long-acting opioids during that same time period. **DESIGN:** A retrospective analysis of the pharmacy database was performed for patients dispensed methadone. Data was compared to the long acting opioid cohort to be able to identify any difference in terminal diagnoses present, and the presence of neuropathic pain in both groups. Methadone daily dosage was also analyzed during this study. **RESULTS:** Four hundred sixteen hospice patients were dispensed methadone over a twelve-month period of time. For comparison, 21,219 patients were prescribed a long-acting opioid preparation (sustained-release morphine, sustained-release oxycodone, or transdermal fentanyl). The most common terminal diagnosis for both groups was lung carcinoma. The distribution of terminal diagnoses was similar in both groups. The group prescribed methadone was found to have a higher incidence of neuropathic pain (30.5% of patients) when compared to the long-acting opioid group (16.9%). Most patients (61.3%) were prescribed daily methadone doses of 100 mg or less. **CONCLUSIONS:** Despite its potential clinical and economic benefits, methadone is not commonly prescribed for the hospice patient in the home-care setting. Clinicians may be more aware of the usefulness of methadone

in the treatment of neuropathic pain.

PMID: 12974826 [PubMed - indexed for MEDLINE]

145: Palliat Med. 2003 Oct;17(7):644-5.

Palliative home care and dying at home is an option for patients living alone.

Gyllenhammar E, Thoren-Todoulos E, Strang P, Strom G, Eriksson K, Kinch M.

Publication Types:

Letter

PMID: 14594159 [PubMed - indexed for MEDLINE]

146: Palliat Med. 2003 Oct;17(7):646-7.

Comment on:

Palliat Med. 2003 Jan;17(1):27-39.

GPs' experiences of palliative care.

Lloyd-Williams M.

Publication Types:

Comment

Letter

PMID: 14594161 [PubMed - indexed for MEDLINE]

147: Palliat Med. 2003 Oct;17(7):648-9.

Insurance cover for research in independent hospices.

Lucas C, Hardy J.

Publication Types:

Letter

PMID: 14594163 [PubMed - indexed for MEDLINE]

148: Palliat Med. 2003 Oct;17(7):650-1.

Comment on:

Palliat Med. 2003 Jul;17(5):393-4.

Euthanasia: on slippery slopes and vulnerable patients.

Materstvedt LJ.

Publication Types:

Comment

Letter

PMID: 14594165 [PubMed - indexed for MEDLINE]

149: Palliat Med. 2003 Oct;17(7):651-2.

Comment on:

Palliat Med. 2003 Mar;17(2):97-101; discussion 102-79.

Concepts and definitions: a source of confusion in the euthanasia debate.

Taboada P.

Publication Types:

Comment

Letter

PMID: 14594166 [PubMed - indexed for MEDLINE]

150: Palliat Med. 2003 Oct;17(7):567-75.

Respite in palliative care: a review and discussion of the literature.

Ingleton C, Payne S, Nolan M, Carey I.

School of Nursing and Midwifery, University of Sheffield, Sheffield, UK.

m.c.ingleton@sheffield.ac.uk

Family caregivers, who are patients' relatives and friends (hereafter called carers), play a significant and arguably most important role in enabling patients to make choices about their place of care during advanced disease and in the terminal phase. Relatively little attention has been directed towards identifying the needs of carers who find themselves in this position and what interventions (if any) might best support them in continuing to provide care to the patient during the illness and dying trajectory. What evidence there is suggests that while some aspects of caring are looked on positively, carers also experience challenges in maintaining their physical and psychological health and their social and financial wellbeing. One common recommendation is that respite facilities be provided. The purpose of this paper is to consider the definitions and assumptions that underpin the term 'respite' and its impact on the physical, psychological and social outcomes of carers in palliative care contexts. We conducted a review of the literature, which involved searching five electronic databases: Web of Science, Medline, CINHAHL, Cochrane Database System Review and

Social Sciences Citation Index. The search identified 260 papers, of which 28 related directly to adult respite care in specialist palliative care. These

papers were largely concerned with descriptive accounts of respite programmes, guidance on referral criteria to respite services or were evaluating the effects of respite on the patient rather than the impact on the carer. We did not identify any empirical studies assessing the effects of respite provided by specialist palliative care services on carer outcomes. There is insufficient evidence to draw conclusions about the efficacy of offering respite care to support carers of patients with advanced disease. We, therefore, draw on the wider literature on carers of adults with chronic disease to consider the impact of respite services and offer suggestions for further research.

Publication Types:

Review

Review, Academic

PMID: 14594147 [PubMed - indexed for MEDLINE]

151: Patient Educ Couns. 2003 Jul;50(3):263-4.

Clinical decision-making at the end of life: the role of the patient's wish.

Visser A, van Leeuwen AF, Voogt E, van der Heide A, van der Rijt K.

Helen Dowling Institute, P.O. Box 85061, 3508 AB, Utrecht, The Netherlands.
a.visser@hdi.nl

Information about medical decision-making in the last stage of life and the wishes of terminally ill patients is scarce. At two hospital departments, we observed 16 multidisciplinary meetings and recorded 110 discussions concerning 74 patients. Thirty-three of these discussions concerned either starting or forgoing potentially life-prolonging therapy or applying potentially life-shortening medical interventions. The wishes of the patients were considered in 15 of these discussions. In 6 of these 15 discussions, the patient's wish was unknown. In five discussions the decision was postponed to enable discussions with the patients. Potentially life-shortening decisions were never made if patients were known to disagree. No decisions about physician-assisted death were made. The study shows that medical end-of-life decisions are commonly shared between the involved caregivers and the patients.

PMID: 12900096 [PubMed - indexed for MEDLINE]

152: Prof Nurse. 2003 Mar;18(7):402-5.

Reflecting on the psychosocial care of patients with a terminal illness.

Stewart M.

Bolton Hospice, Bolton, Lancashire.

The exercise of reflecting on nursing practice and on the theories used to inform that practice can enable nurses to learn to better understand the experiences of patients facing death. By sharing patients' fears and fostering

hope nurses can help them to regain a sense of control over their lives and promote feelings of hope for the time they have left.

PMID: 12674049 [PubMed - indexed for MEDLINE]

153: Provider. 2003 Dec;29(12):20-2, 25-9, 33.

Comfort, compassion, dignity. Mark end-of-life care.

Gold MF.

PMID: 14677249 [PubMed - in process]

154: Psychol Rep. 2003 Oct;93(2):641-2.

Attitudes toward physician-assisted suicide and death anxiety.

Schaller S, Lester D, Abdel-Khalek A.

University of Mannheim.

A scale to measure approval of physician-assisted suicide was devised. Scores on the scale were uncorrelated to death anxiety in a sample of 168 students.

PMID: 14650699 [PubMed - indexed for MEDLINE]

155: Psychooncology. 2003 Sep;12(6):620-7.

Couples therapy at end of life.

Mohr DC, Moran PJ, Kohn C, Hart S, Armstrong K, Dias R, Bergsland E, Folkman S.

University of California, San Francisco, CA, USA. dmohr@itsa.ucsf.edu

This study reports on a preliminary uncontrolled study of a treatment for couples in which one partner is diagnosed with a terminal illness. In this study nine couples, in which one partner was diagnosed with a terminal illness and had less than 18 months to live, were offered eight sessions of couples therapy. Follow-up data were available for six couples. Two patients died during treatment and a third patient moved out of the area prior to completing the follow-up assessment. Significant decreases were seen in the patients' distress about dying and the frequency of partners' worry about their partner dying. Improvements were also seen in relationship quality. While the size of the study precludes generalizing these findings to a larger population, this study supports further exploration of couples therapy as a potentially useful adjunct to end of life care. Copyright 2003 John Wiley & Sons, Ltd.

Publication Types:

Clinical Trial

PMID: 12923802 [PubMed - indexed for MEDLINE]

156: Qual Health Res. 2003 Oct;13(8):1039-62.

Meaning and agency in discussing end-of-life care: a study of elderly veterans' values and interpretations.

Young AJ, Ofori-Boateng T, Rodriguez KL, Plowman JL.

VA Pittsburgh Healthcare System's Geriatric Research, Education, and Clinical Center (GRECC), Department of Neurology, University of Pittsburgh School of Medicine, Pennsylvania, USA.

The authors of this exploratory study used textual analysis of transcribed interviews to examine the mental constructs that individuals form around advance care terminology and to learn how elderly veterans conceptualize the language used in the Veterans Administration advance directive. They found that respondents often negotiated meaning by drawing on rigid schemas, specific mental constructs already in place: The Lord's Will, Machine Talk, Being a Burden, and Being Productive. The authors also examined the transcripts for agency. In addition to assigning external agency for end-of-life care decisions, respondents often expressed a complex interaction of "self" and "other" agency. These results challenge us to develop communication methods that allow patients to claim agency and participate fully in decisions regarding their health care, especially at the end of life.

PMID: 14556418 [PubMed - indexed for MEDLINE]

157: Resuscitation. 2003 Jul;58(1):65-71.

Prevalence of 'do not attempt resuscitation' orders and living wills among patients suffering cardiac arrest in four secondary hospitals.

Skrifvars MB, Hilden HM, Finne P, Rosenberg PH, Castren M.

Department of Anaesthesiology and Intensive Care Medicine, Helsinki University Hospital, P.O. Box 340 FIN-00029 HUS, Helsinki, Finland.
markus.skrifvars@kolumbus.fi

OBJECTIVE: To assess the prevalence and implementation of 'do not resuscitate' orders, nowadays called 'do not attempt resuscitation' (DNAR) orders and living wills among patients suffering in-hospital cardiac arrest (CA) in whom cardiopulmonary resuscitation was not initiated. MATERIALS AND METHODS: A prospective survey of CA patients conducted in four secondary hospitals during 2000-2001. The information collected included the presence of DNAR and a living will and the patients sociodemographic and disease factors and the reasons for not initiating resuscitation when no DNAR order was present. Data on the resuscitated patients were collected according to the Utstein recommendations (analyzed and published separately) and used for comparison. RESULTS: During the study period, 1486 patients suffered CA without resuscitation being initiated.

Data collection was successful in 1143 patients (77%), who were included in the study. Most of the patients (84.5%) had a DNAR order. The prevalence of DNAR orders differed between the participating hospitals ($P < 0.001$), and between the wards of the hospital, with most DNAR orders in the cardiac care unit (100%) and medical wards (87%). The patients designated as DNAR were likely to be older ($P < 0.01$) and of poorer functional status ($P < 0.001$). Reasons for abstaining from resuscitation without a DNAR order were unwitnessed arrest (27%) and terminal disease (66%). Living wills were uncommon (1.5%). Patients with a living will were likely to have a DNAR order ($P < 0.01$). CONCLUSION: Most patients who suffered in-hospital CA without resuscitation had a DNAR order, and, for those who did not, terminal disease and medical futility were evident in most cases. Living wills were uncommon, but they appeared to have had some impact on treatment.

PMID: 12867311 [PubMed - indexed for MEDLINE]

158: Support Care Cancer. 2003 Dec 18 [Epub ahead of print].

Principles of medical ethics in supportive care: a reflection.

O'Hare DG.

School of Public Health, New York Medical College, 10595, Valhalla, New York, NY, USA.

The possibility of medical-moral controversy in contemporary health care delivery is occasioned by the interfacing of expanding technology with both professional and personal value systems, frequent and significant knowledge deficits on the part of health care consumers, and increased circumspection of and economic constraints experienced by health care providers. Particularly in an era of increasing regulatory mandates and the frequent and lamentable decrease in the availability of human, natural, and institutional resources, an understanding of the function of ethical analysis is indigenous to care, which is simultaneously medically appropriate and morally indicated. But while a familiarity with and an appreciation of the potential contribution of ethical reasoning is essential in all health care delivery, it assumes critical importance in supportive care. In that venue, where the rigors and demands of aggressively therapeutic interventions have ceased and the goal and the demeanor of care have shifted to the palliative mode, heightened attention to the principles of medical ethics is necessary for the balancing of rights and responsibilities for health care consumers and providers alike. This issue ultimately can be singularly salient in providing care that is patient centered and directed. Individuals acting as moral agents, suggesting what "ought" to be done in a given situation, either for themselves or as they are involved in rendering or supporting decisions proffered for or by other moral agents, particularly those in extremis, those in the throes of terminal illness following the collapse of the curative mode, need recourse to principles to facilitate their reasoning. Although the employment of each principle of medical ethics offers guidelines for reflection on the most comprehensive and appropriate care, it is attention to autonomy, informed consent, and beneficence that promotes the most effective supportive care. For even as the question of medical viability is settled in favor of palliation over aggression, there remain the entanglements of psychological stability, conflicting value systems,

and the impact of the social milieu as well as the issues of economic responsibility and resource accountability. It is in the attention to the medical ethical principles of autonomy and informed consent, especially as amplified by the creation of and respect for advance directives, that the most holistic and productive supportive care can be offered. It is also in this posture that appeal to the principle of beneficence is made. Just as the progress of disease and, therefore, the realistic goals of care change, so too can an individual's considered opinion with regard to end-of-life decisions. Preserving the integrity of patients and caregivers alike and engaging in fruitful and informative dialog prior to seeking volitional authorization or operationalizing a supportive approach demonstrates renewed concern for both patient autonomy and professional accountability in the provision of a comprehensive end-of-life care plan. Discussions will not be avoided until they can no longer effectively take place, salient questions will not go unanswered, and decisions around end-of-life questions, in the mode of supportive care, will not be absent where care was exercised to engage patients in significant dialog earlier rather than later in their disease processes.

PMID: 14685834 [PubMed - as supplied by publisher]

159: Support Care Cancer. 2003 Nov 20 [Epub ahead of print].

Attitudes to terminal patients' unorthodox therapy: Finnish doctors' responses to a case scenario.

Hinkka H, Kosunen E, Lammi UK, Metsanoja R, Kellokumpu-Lehtinen P.

Kangasala Health Center, Herttualantie 28, 36200, Kangasala, Finland.

We carried out a postal survey of a sample of Finnish doctors (n=1182) concerning their attitudes and ethical decisions in end-of-life care. A scenario was presented in which a patient with terminal cancer wished to obtain unorthodox treatment. Factors possibly influencing decision making such as general attitudes, life values and demographics were investigated. The response rate was 62%. The patient's plan to use unorthodox treatment was accepted by 54% of doctors. Gender or speciality did not influence the decision, but doctor's age was a significant factor (P=0.0005). Doctors aged 35-49 years were more accepting; younger and older ones less accepting. Doctors who had clinical experience in terminal care were more compliant to the patient's plan (P=0.034). A stepwise logistic regression analysis was used to create a model for explaining not accepting versus accepting the treatment with the background variables. Altogether eight independent significant variables were included in the final model of explaining a doctor's choice in the presented scenario. According to the model the patient's wish was more frequently accepted if the doctor was middle-aged, had clinical experience in terminal care, valued a high standard of living, considered terminal care satisfying, was less critical of health economics, considered advance directives helpful, had a high fear-of-death index score, and valued professional status less.

PMID: 14628213 [PubMed - as supplied by publisher]

160: Support Care Cancer. 2003 Aug;11(8):509-15. Epub 2003 Apr 17.

Multiprofessional team approach in palliative care units in Japan.

Maeyama E, Kawa M, Miyashita M, Ozawa T, Futami N, Nakagami Y, Sugishita C, Kazuma K.

Department of Adult Nursing/Terminal and Long-term Care Nursing, School of Health Sciences and Nursing, Graduate School of Medicine, The University of Tokyo, 7-3-1 Hongo, Bunkyo-Ku, 113-0033, Tokyo, Japan. emaeayama-
tky@umin.ac.jp

Health-care providers engaged in palliative care experience difficulty with the practice of team care. However, the details of the difficulties have not been clarified. To obtain an overview of team care in the Japanese palliative inpatient care setting, a descriptive and cross-sectional study was performed. The participants were physicians, nurses, dietitians, medical social workers (MSWs), and pharmacists. A representative from each discipline was selected. They were asked about their participation in services provided by government-approved palliative care units (PCUs) and the practice of team care. A total of 38 institutions participated in this study. In these institutions, 97% of physicians, 37% of dietitians, 39% of MSWs, 27% of pharmacists, and 13% of physical therapists attended PCU care meetings once a week or more, and 35% of religious workers and 11% of counselors attended. About 70% of institutions held regular care meetings with more than three types of health-care providers. Physicians and nurses had different perceptions regarding the practice of team care. The former had a positive perception of team care and the latter had a negative perception. In addition, nurses' perception of overall team care was related to their perception of care meetings ($P=0.052$) and the number of types of professional participating in care meetings ($P=0.054$). To promote team care in the Japanese palliative care setting, it is necessary to consider a practical standard of team care, and to conduct effective care meetings.

PMID: 12700953 [PubMed - indexed for MEDLINE]

161: Surviv News (Atlanta Ga). 2003 Nov-Dec;:9.

"Hereby devised and bequeathed".

Carraway G.

Publication Types:
Newspaper Article

PMID: 14696578 [PubMed - indexed for MEDLINE]

162: West J Nurs Res. 2003 Oct;25(6):652-66; discussion 667-75.

Communicating end-of-life preferences.

McDonald DD, Deloge JA, Joslin N, Petow WA, Severson JS, Votino R, Shea MD,

Drenga JM, Brennan MT, Moran AB, Del Signore E.

University of Connecticut, School of Nursing, USA.

The purpose of this survey was to explore how adults communicate their end-of-life preferences. Face-to-face interviews were conducted with 119 community-dwelling adults who had previously engaged in conversations about their end-of-life preferences. Factors that made it easier to initiate the discussion included having personal experience with illness or death (24.4%), being straightforward (24.4%), or having someone else facilitate the discussion (11.8%). Most described vague end-of-life preferences such as not wanting any machines (41.2%) or heroics (34.5%). Although 22.7% reported using a living will to make their preferences clear, only 5.9% mentioned repeating or reinforcing their preferences. In all, 21% had discussed their end-of-life preferences with their physicians. These findings show discussions about end-of-life preferences frequently lack the clarity and detail needed by significant others and health care providers to honor the preferences. Routine dialogue with health care providers and significant others about end-of-life preferences might provide greater clarity and comfort.

PMID: 14528616 [PubMed - indexed for MEDLINE]