



END OF LIFE CARE BIBLIOGRAPHY July 2004

Acad Med. 2004 Jun;79(6):541-8.

More training needed in chronic care: a survey of US physicians.

Darer JD, Hwang W, Pham HH, Bass EB, Anderson G.

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PURPOSE: Although more than 125 million North Americans have one or more chronic conditions, medical training may not adequately prepare physicians to care for them. The authors evaluated physicians' perceptions of the adequacy of their chronic illness care training to and the effects of training on their attitudes toward care of persons with chronic conditions. **METHOD:** In November 2000 through June 2001, the authors surveyed by telephone a random sample of U.S. physicians who had > or =20 hours of patient contact per week. The interview instrument examined demographics, career satisfaction, practice characteristics, perceived adequacy of chronic illness care training in ten competencies (geriatric syndromes, chronic pain, nutrition, developmental milestones, end-of-life care, psychosocial issues, patient education, assessment of caregiver needs, coordination of services, and interdisciplinary teamwork), and effect of training on attitudes toward chronic illness care. **RESULTS:** Of 1,905 eligible physicians, 1,236 (65%) responded (270 family or general practitioners, 231 internists, 129 pediatricians, 335 nonsurgical specialists, and 271 surgeons). Most physicians reported their chronic disease training was less than adequate for all ten competencies. Family practitioners were more likely ($p < .05$) to report adequate training in seven competencies compared with internists, and in two to four competencies when compared with pediatricians, nonsurgical specialists, or surgeons. Most physicians reported that training had a positive effect on attitudes toward care of people with chronic conditions, including the ability to make a difference in their lives (74-84%). **CONCLUSIONS:** Physicians perceived their medical training for chronic illness care was inadequate. Medical schools and residencies may need to modify curricula to better prepare physicians to treat the growing number of people with chronic conditions.

PMID: 15165973 [PubMed - indexed for MEDLINE]

2: Aging Clin Exp Res. 2004 Apr;16(2):87-103.

Death and dying from old people's point of view. A literature review.

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Providing high-quality end-of-life care to older people is a requirement especially for countries with a high proportion of old and very old people. This calls for an understanding of older people's view of death and dying, and one way forward is to investigate the current knowledge base. This study aimed at reviewing the literature of empirical studies about older people's view of death and dying, whether in a terminal phase of life or not. A total of 33 publications were included, identified in a stepwise literature search done in Medline, CINAHL and PsychInfo, using the terms "death", "attitude to death", "death" and "dying" in combination with "aged". Very few studies focused solely on the oldest old. The designs were mainly cross-sectional, quantitative or qualitative, using personal interviews. Some common themes of importance for further research were revealed, such as older people's readiness to talk about death and dying, conceptions of death, after-death and dying, and were seemingly related to anxiety about death, the impact on and of those close by, having both negative and positive connotations, especially related to balancing closeness, being a burden and dependency, death anxiety and its possible antecedents, the fine line between natural sadness and suffering from depression, and worry about the end-of-life phase. The lack of studies dealing with older people's view of death and dying, and the heterogeneity with regard to research questions and samples implies that findings may serve mainly as inspiration for further research.

PMID: 15195983 [PubMed - in process]

3: Am Fam Physician. 2004 May 15;69(10):2322.

Comment on:

Am Fam Physician. 2003 May 1;67(9):2025-6, 2028.

How should physicians decide to resuscitate a patient?

Hanson S.

Publication Types:

Comment
Letter

PMID: 15168955 [PubMed - indexed for MEDLINE]

4: Am J Geriatr Cardiol. 2004 Mar-Apr;13(2):92-4.

Ethical issues in the management of geriatric cardiac patients.

Basta LL.

The University of South Florida, Project GRACE, Clearwater, FL 33756, USA.

Publication Types:
Case Reports

PMID: 15010656 [PubMed - indexed for MEDLINE]

5: Am J Hosp Palliat Care. 2004 May-Jun;21(3):233-6.

Honoring the patient's wishes or passive euthanasia?

Baumrucker SJ, Rousseau P, Morris GM, Stolick M, Hentz P.

Quillen College of Medicine, Rogersville, Tennessee, USA.

Publication Types:
Case Reports

PMID: 15188925 [PubMed - indexed for MEDLINE]

6: Am J Hosp Palliat Care. 2004 May-Jun;21(3):209-15.

Joining forces, joining futures: hospice at the crossroads.

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Faced with health-policy changes, increased competition, and limited funding, hospices must either find more efficient ways to provide end-of-life care or risk organizational demise. Increasingly, hospices are re-evaluating their organizations to stretch resources and remain viable. Prevalent restructuring options for addressing environmental pressures are integration, alliance, and collaboration with other organizations. This study examines the restructuring phenomenon by evaluating trends among nonprofit hospices in six states. The study identifies demographic characteristics predictive of organizational decisions to join forces, and it examines the dominant political and economic reasons that propel or impede restructuring decisions. In addition, the study evaluates the results of restructuring actions.

PMID: 15188921 [PubMed - indexed for MEDLINE]

7: Am J Hosp Palliat Care. 2004 May-Jun;21(3):203-8.

Religious maturity in the midst of death and dying.

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Healthy religious experience is defined by certain qualities of expression. In an effort to explore the concept of mature religious phenomenology, this article includes descriptions of two encounters from personal pastoral experience. The first encounter shows how a person with an unhealthy religious experience faces death. The second encounter describes an expression of mature religious experience in the face of death and how a pastoral caregiver can facilitate its outcome. This is followed by a pastoral theological response.

PMID: 15188920 [PubMed - indexed for MEDLINE]

8: Am J Hosp Palliat Care. 2004 May-Jun;21(3):191-5.

Telehospice in Michigan: use and patient acceptance.

Whitten P, Doolittle G, Mackert M.

Department of Telecommunications, Michigan State University, East Lansing, Michigan, USA.

Telehospice, the use of telemedicine technologies to provide services to hospice patients, offers an innovative solution to the challenges of providing high-quality, cost-effective end-of-life care. Specifically, the technology allows caregivers to transmit video images of patients, which provide off-site nurses with the information they need to assist the caregiver. Our telehospice project was conducted in urban and rural Michigan between 2000-2002 and collected data from 187 patients receiving telehospice services in their homes during this study. Overall, nurses were the primary providers of telehospice services and initiated the majority of routine televisits. Often, patients who described themselves as "overwhelmed" at the time of enrollment declined telehospice. However, patients were extremely satisfied with telehospice and often expressed frustration that nurses did not use the telehospice equipment more frequently.

PMID: 15188918 [PubMed - indexed for MEDLINE]

9: Am J Hosp Palliat Care. 2004 May-Jun;21(3):167-8.

Dying alone with the TV.

Gelo F.

Publication Types:
Editorial

PMID: 15188914 [PubMed - indexed for MEDLINE]

10: Arch Pediatr Adolesc Med. 2004 May;158(5):415-8.

Comment on:

Library Program Office
Office of Information
Veterans Health Administration

Arch Pediatr Adolesc Med. 2004 May; 158(5): 430-5.

Perspectives on quality at the end of life.

Feudtner C.

Publication Types:

Comment
Editorial

PMID: 15123468 [PubMed - indexed for MEDLINE]

11: BMC Public Health. 2003 Oct 23; 3(1):33.

Current HIV/AIDS end-of-life care in sub-Saharan Africa: a survey of models, services, challenges and priorities.

Harding R, Stewart K, Marconi K, O'Neill JF, Higginson IJ.

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BACKGROUND: In response to increased global public health funding initiatives to HIV/AIDS care in Africa, this study aimed to describe practice models, strategies and challenges to delivering end-of-life care in sub-Saharan Africa. **METHODS:** A survey end-of-life care programs was conducted, addressing the domains of service aims and configuration, barriers to pain control, governmental endorsement and strategies, funding, monitoring and evaluation, and research. Both closed and qualitative responses were sought. **RESULTS:** Despite great structural challenges, data from 48 programs in 14 countries with a mean annual funding of US 374,884 dollars demonstrated integrated care delivery across diverse settings. Care was commonly integrated with all advanced disease care (67%) and disease stages (65% offering care from diagnosis). The majority (98%) provided home-based care for a mean of 301 patients. Ninety-four percent reported challenges in pain control (including availability, lack of trained providers, stigma and legal restrictions), and 77% addressed the effects of poverty on disease progression and management. Although 85% of programs reported Government endorsement, end-of-life and palliative care National strategies were largely absent. **CONCLUSIONS:** The interdependent tasks of expanding pain control, balancing quality and coverage of care, providing technical assistance in monitoring and evaluation, collaborating between donor agencies and governments, and educating policy makers and program directors of end-of-life care are all necessary if resources are to reach their goals.

PMID: 14572317 [PubMed - indexed for MEDLINE]

12: BMJ. 2004 Jun 12; 328(7453):1440.

Comment on:

BMJ. 2004 May 8; 328(7448):1088-9.

Am I breaking the law again?

Irwin M.

Publication Types:
Comment
Letter

PMID: 15191995 [PubMed - indexed for MEDLINE]

13: BMJ. 2004 Jun 5;328(7452):1337.

Appeal court upholds Oregon's assisted suicide law.

Charatan F.

Publication Types:
News

PMID: 15178604 [PubMed - indexed for MEDLINE]

14: BMJ. 2004 Jun 5;328(7452):1336.

Dutch reporting of euthanasia cases falls--despite legal reporting requirements.

Sheldon T.

Publication Types:
News

PMID: 15178601 [PubMed - indexed for MEDLINE]

15: Bull Group Int Rech Sci Stomatol Odontol. 2003 May-Dec;45(2-3):52-5.

In favour or against euthanasia--dentistry students' opinion.

Matthews-Brzozowska M, Filipowski H, Musielak M, Matthews-Brzozowska T.

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Euthanasia and a doctor-assisted suicide are not only practiced worldwide, but also legalized in some countries. In Poland they are broadly discussed. The purpose of this paper was to define dentistry students attitude towards human right to ask for death and euthanasia. In the research 148 students of both sexes were questioned. Generally students were against euthanasia in the world as well as in Poland, although men were in majority for euthanasia. Believers were against it due to ethically-religious reasons, while non-believers were for euthanasia motivating it by rational reasons.

PMID: 15148876 [PubMed - indexed for MEDLINE]

16: Can J Anaesth. 2004 Jun;51(6):631-6.

Simple changes can improve conduct of end-of-life care in the intensive care unit: [Des changements simples peuvent améliorer les soins aux mourants à l'unité des soins intensifs].

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PURPOSE: To describe changes to the conduct of withdrawal of life support (WOLS) in two teaching hospital tertiary care medical surgical intensive care units (ICUs) in a single centre over two distinct time periods. **METHODS:** We used a retrospective chart review with a before and after comparison. We assessed aspects of end-of-life care for ICU patients dying after a WOLS before and after we introduced instruments to clarify do not resuscitate (DNR) orders and to standardize the WOLS process, sought family input into the conduct of end-of-life care, and modified physicians' orders regarding use of analgesia and sedation. **RESULTS:** One hundred thirty-eight patients died following life support withdrawal in the ICUs between July 1996 and June 1997 (PRE) and 168 patients died after a WOLS between May 1998 and April 1999 (POST). Time from ICU admission to WOLS (mean +/- SD) was shorter in the POST period (191 +/- 260 hr PRE vs 135 +/- 205 hr POST, $P = 0.05$). Fewer patients in the POST group received cardiopulmonary resuscitation in the 12-hr interval prior to death (PRE = 7; POST = 0; $P < 0.05$). Fewer comfort medications were used (PRE: 1.7 +/- 1.0 vs POST: 1.4 +/- 1.0; $P < 0.05$). Median cumulative dose of diazepam (PRE: 20.0 vs POST: 10.0 mg; $P < 0.05$) decreased. Documented involvement of physicians in WOLS discussions was unchanged but increased for pastoral care (PRE: 10/138 vs POST: 120/168 cases; $P < 0.05$). The majority of nurses (80%) felt that the DNR and WOLS checklists led to improved process around WOLS. **CONCLUSION:** Simple changes to the process of WOLS can improve conduct of end-of-life care in the ICU.

PMID: 15197128 [PubMed - in process]

17: Can J Anaesth. 2004 Jun;51(6):623-630.

Most critically ill patients are perceived to die in comfort during withdrawal of life support: a Canadian multicentre study: [Les grands malades meurent sans souffrance pendant le retrait du maintien des fonctions vitales : une étude canadienne].

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PURPOSE: Most deaths in intensive care units (ICUs) follow a withdrawal of life support (LS). Evaluation of this process including the related perspectives of grieving family members is integral to improvement of palliation in the ICU. **METHODS:** A prospective, multicentre, cohort study in six Canadian university-affiliated ICUs included 206 ICU patients (length of stay ≥ 48 hr) who received mechanical ventilation (MV) before LS withdrawal. We recorded modes, sequence and time course of LS withdrawal and drug usage (4 hr before; 4-8 hr and 8-12 hr before death). We asked a specified family member to assess patient comfort and key aspects of end-of life care. **RESULTS:** MV was withdrawn from 155/206 (75.2%) patients; 97/155 (62.6%) died after extubation and 58/155 (37.4%) died with an airway in place. The most frequently used drugs and the cumulative doses [median (range)] in the four hours before death were: morphine 119/206, 24 mg, (2-450 mg); midazolam 45/206, 24 mg, (2-380 mg); and lorazepam 35/206, 4 mg, (1-80 mg). These doses did not differ among the three time periods before death. Of 196 responses from family members most indicated that patients were perceived to be either totally (73, 37.2%), very (48, 24.5%), or mostly comfortable (58, 29.6%). Times to death, morphine use and family members' perceptions of comfort were similar for each type of change to MV. **CONCLUSIONS:** Most patients were perceived by family members to die in comfort during a withdrawal of LS. Perceptions of patient comfort and drug use in the hours before death were not associated with the mode or sequence of withdrawal of LS, or the time to death.

PMID: 15197127 [PubMed - as supplied by publisher]

18: Can J Anaesth. 2004 Mar;51(3):266-72.

Dying in the ICU: strategies that may improve end-of-life care.

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PURPOSE: Since 10 to 20% of adult patients admitted to the intensive care unit (ICU) in Canada die, addressing the needs of dying critically ill patients is of paramount importance. The purpose of this article is to suggest some strategies to consider to improve the care of patients dying in the ICU. **SOURCE:** Data sources were randomized clinical trials, observational studies and surveys. We purposively selected key articles on end-of-life care to highlight eight initiatives that have the potential to improve care for dying critically ill patients. These initiatives were presented at the International Consensus Conference on End-of-Life Care in the ICU on April 24-25, 2003 in Brussels, Belgium. **PRINCIPAL FINDINGS:** We describe eight strategies that, if adopted, may positively impact on the end-of-life care of critically ill patients: 1) promote social change through professional initiatives; 2) legitimize research in end-of-life care; 3) determine what dying patients need; 4) determine what

families of dying patients need; 5) initiate quality improvement locally; 6) use quality tools with care; 7) educate future clinicians; and 8) personally engage in end-of-life care. Most of these strategies have not been subjected to rigorous evaluation. CONCLUSION: Adoption of some of these strategies we describe may lead to improved end-of-life care in the ICU. Future studies should include more formal evaluation of the efficacy of end-of-life interventions to help us ensure high quality, clinically relevant, culturally adapted care for all dying critically ill patients.

PMID: 15010412 [PubMed - indexed for MEDLINE]

19: Caring. 2004 May;23(5):50-1.

Older nurses embrace hospice & home care.

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Older nurses who have "done their time" in hospital wards sometimes find home health or hospice nursing a welcome and rewarding change of pace. While their maturity often gives them the empathy and compassion that can bring comfort to their patients, their extensive experience supplies them with the knowledge they need to work confidently in an independent setting.

PMID: 15168577 [PubMed - indexed for MEDLINE]

20: Caring. 2004 May;23(5):44-9.

Photo postcard campaign puts human faces on home care & hospice.

[No authors listed]

PMID: 15168576 [PubMed - indexed for MEDLINE]

21: Caring. 2004 May;23(5):42-3.

Home care aides reaping personal rewards.

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PMID: 15168575 [PubMed - indexed for MEDLINE]

22: Caring. 2004 May;23(5):40-1.

The best birthday present.

Romersberger A, Knowles K, McKee J.

PMID: 15168574 [PubMed - indexed for MEDLINE]

23: Caring. 2004 May;23(5):24-34.

Ross' story. One man's triumphant journey through life and death.

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PMID: 15168572 [PubMed - indexed for MEDLINE]

24: Caring. 2004 May;23(5):18-20.

A world apart. The challenges and rewards of rural hospice.

Braveman C.

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PMID: 15168571 [PubMed - indexed for MEDLINE]

25: CMAJ. 2004 Jun 8;170(12):1811-2.

Comment on:

CMAJ. 2004 Jun 8;170(12):1795-801.

Family care and burden at the end of life.

Zarit SH.

Department of Human Development and Family Studies, Pennsylvania State

University, University Park, 16802-6505, USA. z67@psu.edu

Publication Types:

Comment

PMID: 15184336 [PubMed - indexed for MEDLINE]

26: Community Ment Health J. 2004 Feb;40(1):3-16.

End-of-life care and mental illness: a model for community psychiatry and beyond.

Candilis PJ, Foti ME, Holzer JC.

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End-of-life care is often influenced by the stereotyping of patients by age, diagnosis, or cultural identity. Two common stereotypes arise from the presumed incompetence of many patients to contribute to end-of-life decisions, and the fear that the discussions themselves will be de-stabilizing. We present a model for end-of-life discussions that combines competence assessment with healthcare preferences in a psychiatric population that faces identical stereotypes. The model, which draws on clinical research in competence and suicide risk assessment, has important implications for all patients in the community who are marginalized or stereotyped during discussions of end-of-life treatment.

PMID: 15077725 [PubMed - indexed for MEDLINE]

27: Crit Care Med. 2004 Jul;32(7):1484-1488.

Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction.

McDonagh JR, Elliott TB, Engelberg RA, Treece PD, Shannon SE, Rubenfeld GD, Patrick DL, Curtis JR.

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OBJECTIVE: Family members of critically ill patients report dissatisfaction with family-clinician communication about withdrawing life support, yet limited data exist to guide clinicians in this communication. The hypothesis of this analysis was that increased proportion of family speech during ICU family conferences would be associated with increased family satisfaction. **DESIGN:** Cross-sectional study. **SETTING:** We identified family conferences in intensive care units of four Seattle hospitals during which discussions about withdrawing life support were likely to occur. **PARTICIPANTS:** Participants were 214 family members from 51 different families. There were 36 different physicians leading the conferences, as some physicians led more than one conference. **INTERVENTIONS:** Fifty-one conferences were audiotaped. **MEASUREMENTS:** We measured the duration of time that families and clinicians spoke during the conference. All participants were given a survey assessing satisfaction with communication. **RESULTS:** The mean conference time was 32.0 mins with an sd of 14.8 mins and a range from 7 to 74 mins. On average, family members spoke 29% and clinicians spoke 71% of the time. Increased proportion of family speech was significantly associated with increased family satisfaction with physician communication. Increased proportion of family speech was also associated with decreased family ratings of conflict with the physician. There was no association between the duration of the conference and family satisfaction. **CONCLUSIONS:** This study suggests that allowing family members more opportunity to speak during conferences may improve family satisfaction. Future studies should assess the effect of interventions to increase listening by critical care

clinicians on the quality of communication and the family experience.

PMID: 15241092 [PubMed - as supplied by publisher]

28: Crit Care Med. 2004 May; 32(5):1230-1.

Comment on:

Crit Care Med. 2004 May; 32(5):1141-8.

Improving end-of-life care: targeting what we can.

Keenan SP.

Publication Types:

Comment

Editorial

Review

Review, Tutorial

PMID: 15190981 [PubMed - indexed for MEDLINE]

29: Crit Care Med. 2004 May; 32(5):1141-8.

Comment in:

Crit Care Med. 2004 May; 32(5):1230-1.

Evaluation of a standardized order form for the withdrawal of life support in the intensive care unit.

Treece PD, Engelberg RA, Crowley L, Chan JD, Rubenfeld GD, Steinberg KP, Curtis JR.

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OBJECTIVE: The intensive care unit remains a setting where death is common, and a large proportion of these deaths are preceded by withdrawal of life support. We describe a quality improvement project implementing and evaluating a "withdrawal of life support order form" to improve quality of end-of-life care in the intensive care unit. **DESIGN:** Before-after evaluation. **SETTING:** County-owned, university-operated, tertiary, level I trauma center. **SUBJECTS:** Subjects were 143 nurses and 61 physicians. **INTERVENTIONS:** We conducted a before-after evaluation of the order form's implementation. The order form has sections on preparations, sedation/analgesia, withdrawal of mechanical ventilation, and the principles of life support withdrawal. To evaluate the form, we surveyed intensive care unit clinicians regarding satisfaction with the form, measured nurse-assessed quality of dying and death with a 14-item survey (scored 0 for worst possible death to 100 for best possible), and performed chart review to assess narcotic and benzodiazepine use and time from ventilator withdrawal to death. **MEASUREMENTS AND MAIN RESULTS:** We surveyed 143 nurses and 61 physicians about satisfaction with the form. Among nurses reporting that the

form was used (n = 73), most (84%) reported that the order form was helpful and they were most satisfied with the sedation and mechanical ventilation sections. Almost all physicians found the form helpful (95%), and > 70% of physicians found three of the four sections helpful (sedation, mechanical ventilation, and preparations). We obtained quality of dying and death scores for 41 patient deaths before and 76 deaths after the intervention. These scores did not significantly change (mean preintervention score, 78.3; mean postintervention score, 74.2; p = .54) before and after the intervention. Total doses of narcotics and benzodiazepines increased after implementation of the order form in the hour before ventilator withdrawal, the hour after ventilator withdrawal, and the hour before death (p < or = .03). There was no change in the median time from ventilator withdrawal to death (preintervention 37 mins, postintervention 39 mins; p = .49). CONCLUSIONS: Nurses and physicians found the withdrawal of life support order form helpful. The order form did not improve nurses' assessment of patients' dying experience. Medications for sedation increased during the postorder form period without evidence of significantly hastening death. Although the order form was helpful to clinicians and changed medication delivery, demonstrating clear improvements in quality of dying may require larger sample sizes, more sensitive measures, or more effective interventions.

Publication Types:
Evaluation Studies

PMID: 15190964 [PubMed - indexed for MEDLINE]

30: Curr Surg. 2003 Jul-Aug;60(4):360-4.

Comment on:
Aging Ment Health. 2002 Nov;6(4):402-12.
BMC Med Ethics. 2002 Aug 12;3(1):E3.
Br J Surg. 2001 Sep;88(9):1153-4.
J Crit Care. 2002 Sep;17(3):147-60.

When is it really over? Issues confronting surgeons who practice in the surgical intensive care units regarding end-of-life care.

Metzler MH.

University of Missouri-Columbia, Columbia, Missouri, USA.

Publication Types:
Comment

PMID: 15212027 [PubMed]

31: Dimens Crit Care Nurs. 2004 Mar-Apr;23(2):89-92.

End-of-life education in undergraduate nursing curricula.

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Library Program Office
Office of Information
Veterans Health Administration

Americans are increasingly dying in hospitals. The provision of end-of-life care is essential to providing a death with dignity. However, this is not taught in many schools of nursing. The purpose of this article is to discuss the importance of including this important content in nursing curricula.

Publication Types:

Review

Review, Tutorial

PMID: 15192371 [PubMed - indexed for MEDLINE]

32: Ethics Med. 2003 Summer;19(2):103-13.

"Do everything!" Encountering "futility" in medical practice.

Nelson SN.

MeritCare Medical Group, Fargo, North Dakota, USA.

PMID: 15025117 [PubMed - indexed for MEDLINE]

33: Ethics Med. 2001 Spring;17(1):7-12.

Update: the legalization of euthanasia in the Netherlands.

Jochemsen H.

Lindeboom Instituut for Medical Ethics, Free University of Amsterdam, The Netherlands.

PMID: 15080129 [PubMed - indexed for MEDLINE]

34: Eur J Health Law. 2003 Dec;10(4):359-67.

Terminal sedation: a legal approach.

Gevers S.

PMID: 15176131 [PubMed - indexed for MEDLINE]

35: Geriatr Nurs. 2004 May-Jun;25(3):149-56, 163.

Assisted living: aging in place and palliative care.

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Principles of upstream palliative care can guide the planning, programs, and services associated with aging in place in assisted living residences (ALRs). Frail older adults who do not need a nursing home level of care are choosing to live-and die-in ALRs. This article describes the context of assisted living, resident characteristics, key indicators of palliative care, barriers to end-of-life care, and the role, responsibilities, and potential for professional nursing in assisted living. Stakeholder concerns about staff knowledge and skills in care of the elderly, medication management, the risks associated with residential care, and nursing delegation are discussed.

PMID: 15197374 [PubMed - in process]

36: Gerontologist. 2004 Apr; 44(2):159-65.

Nursing facility compliance with do-not-hospitalize orders.

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PURPOSE: This study sought to determine whether nursing homes comply with residents' do-not-hospitalize (DNH) orders prohibiting inpatient hospitalization. **DESIGN AND METHODS:** With the use of data from the nationally representative 1996 Nursing Home Component of the Medical Expenditure Panel Survey, a multivariate logistic regression model was developed. **RESULTS:** Three percent of residents had DNH orders. These residents were half as likely to be hospitalized. Residents in not-for-profit or public facilities were less likely to be hospitalized than those in for-profit homes. Hospitalization was more likely among men, racial or ethnic minorities, those with more diagnosed health conditions, and those in facilities in the South compared with those in the Midwest. Hospitalized residents with DNH orders had no limitations of activities of daily living, were not located in hospital-based nursing homes, were less likely to be in a for-profit facility, and were sicker than nonhospitalized residents with DNH orders. **IMPLICATIONS:** Improved education regarding advance directives, particularly DNH orders, is necessary for health care practitioners and patients. More consistent and rigorous policies should be implemented in nursing facilities.

PMID: 15075412 [PubMed - indexed for MEDLINE]

37: Health Aff (Millwood). 2004 May-Jun; 23(3):228-32.

So tired of life.

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Publication Types:
Case Reports

PMID: 15160821 [PubMed - indexed for MEDLINE]

38: Health Aff (Millwood). 2004 May-Jun; 23(3): 194-200.

Place of death: U.S. trends since 1980.

Flory J, Yinong YX, Gurol I, Levinsky N, Ash A, Emanuel E.

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Place of death is one indicator of the state of end-of-life care. We examine trends in national death certificate data on place of death from 1980 to 1998. During these years the percentage of Americans dying as hospital inpatients decreased from approximately 54 percent to 41 percent. About 310,000 fewer people died in the hospital in 1998 than if the proportion of inpatient deaths had not changed since 1980. For certain diseases the change was much greater. In 1980 whites and African Americans died in the hospital in equal proportions, but in 1998 whites died as inpatients less often than African Americans. These racial differences and their implications deserve further study.

PMID: 15160817 [PubMed - indexed for MEDLINE]

39: HEC Forum. 2004 Mar; 16(1): 38-44.

Comment on:

HEC Forum. 2004 Mar; 16(1): 27-37.

HEC Forum. 2004 Mar; 16(1): 6-26.

Social restrictions on informed consent: research ethics and medical decision making.

May T.

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Publication Types:

Comment

PMID: 15181669 [PubMed - indexed for MEDLINE]

40: HEC Forum. 2004 Mar; 16(1): 27-37.

Comment in:

HEC Forum. 2004 Mar; 16(1): 38-44.

From informed consent to substituted judgment: decision-making at the

end-of-life.

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Publication Types:

Legal Cases

PMID: 15181668 [PubMed - indexed for MEDLINE]

41: Int J Palliat Nurs. 2004 May;10(5):236-41; discussion 242-3.

Voluntary refusal of food and fluids: attitudes of Oregon hospice nurses and
social workers.

Harvath TA, Miller LL, Goy E, Jackson A, Delorit M, Ganzini L.

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As the ethical debate about euthanasia and physician-assisted suicide (PAS) continues, one alternative that has been suggested is for the patient to voluntarily refuse all food and fluids (VRFF). The article describes the results of a study of hospice nurses' and social workers' attitudes towards VRFF and compares them with their attitudes towards PAS. In 2001, a questionnaire was posted to nurses and social workers who care for Oregon residents enrolled in hospice programmes to determine their attitudes towards PAS and VRFF. In general, hospice workers expressed support for patients who choose to hasten their death by VRFF; they were less supportive of PAS. The results from this study suggest that perceptions regarding VRFF are significantly different from those regarding PAS. These results may have important clinical implications for nurses and social workers involved in end-of-life care who encounter patients who wish to hasten their deaths.

PMID: 15215708 [PubMed - in process]

42: Int J Palliat Nurs. 2004 May;10(5):225-35; discussion 235.

Responding to persistent requests for assistance in dying: a phenomenological inquiry.

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Little is known about how American nurses understand and respond to requests made by decisionally capable patients for assistance in dying. This article is based on a broader qualitative study first reported elsewhere (Schwarz, 2003).

The study used phenomenological interpretation and analysis of stories told by 10 nurses who worked in home hospice, critical care, and HIV/AIDS care settings. Persistent requests for assistance in dying were relatively uncommon, but when heard, participants provided the following responses: refusing assistance, administering palliative drugs that might secondarily hasten dying, tacitly permitting and not interfering with patient or family plans to hasten death, and actively providing direct assistance in dying. Nurses' responses were context-driven; they did not seek guidance from professional codes of ethics or colleagues. Secrecy and collusion were routinely practised. Few participants unequivocally agreed or refused to help patients die; most struggled to find morally and legally acceptable ways to help patients die well. Regardless of how they responded, nurses who believed they had hastened death described feelings of guilt and moral distress. Healthcare professionals who provide care for symptomatic dying patients need opportunities to meet with supportive colleagues, to share the experience of troubling cases and of moral conflict, and to be supported and heard in a 'safe' environment.

PMID: 15215707 [PubMed - in process]

43: Int J Palliat Nurs. 2004 Apr;10(4):202-3.

Reflections on the contribution of Frances Sheldon.

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Publication Types:

- Biography
- Historical Article
- Letter

Personal Name as Subject:

Sheldon F

PMID: 15150456 [PubMed - indexed for MEDLINE]

44: Int J Palliat Nurs. 2004 Apr;10(4):185-93; discussion 193.

Attitudes towards end-of-life care in a geriatric hospital in Japan.

Schreiner AS, Hara N, Terakado T, Ikegami N.

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Nursing and medical staff attitudes toward end-of-life care at a private, not-for-profit geriatric hospital in Japan were measured as part of a larger intervention study to develop a palliative care programme. The intervention consisted of focus groups, education with pre- and post-testing, and

attitude/belief surveys. All the medical staff (n = 8) and 99% (n = 97) of the nursing staff participated. Nursing staff overwhelmingly agreed that a palliative care programme would improve end-of-life care (94.6%) and that nurses should be more involved in discussing treatment options with families (85.7%). Of the nursing staff, 88.7% did not agree that doctors currently spend enough time discussing care plans with patients/families. The main barriers to improving end-of-life care perceived by the nursing staff were the treatment-oriented attitude of the doctors and their limited communication skills. The main barriers perceived by doctors were the lack of alternatives to their medical approach and legal concerns. The findings suggest that improving doctor/nurse communication would facilitate the development of a palliative care programme at this hospital.

PMID: 15150454 [PubMed - indexed for MEDLINE]

45: Int J Palliat Nurs. 2004 Apr;10(4):180-4.

A difficult relationship between oncology ward staff and a patient's husband: a case study.

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Publication Types:
Case Reports

PMID: 15150453 [PubMed - indexed for MEDLINE]

46: Int J Palliat Nurs. 2004 Apr;10(4):173-9.

Dignity-conserving care: application of research findings to practice.

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A central tenet of palliative care is to help people die with "dignity". The widespread use of this term presupposes that this construct is well understood from the perspective of the terminally ill, and that the factors that bolster or erode dignity are known. However, the paucity of research related to these issues suggests otherwise. Over the past 5 years, this research team, headed by Dr Chochinov, has undertaken a programme of research aimed at explicating what dignity means to those who are terminally ill, and identifying those factors that support and undermine dignity in this patient population. This article will provide a synopsis of that work, with an emphasis on the application of research findings for practice.

PMID: 15150452 [PubMed - indexed for MEDLINE]

47: Int J Palliat Nurs. 2004 Apr;10(4):160.

Integrated care: hospice and palliative care services lead the way.

Howell D.

Publication Types:
Editorial

PMID: 15150449 [PubMed - indexed for MEDLINE]

48: Int J Palliat Nurs. 2004 Mar;10(3):133-43.

The experience of family members caring for a dying loved one.

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Qualitative nursing research into the experience of family members caring for a dying loved one has been limited. This study used a phenomenological approach to explore this experience. The pattern of caring for a dying loved one and its intertwined dimensions were described. Caregivers felt a sense of helplessness that was associated with illness progression, their inability to relieve pain and discomfort, and decision-making related to patient admission to a palliative care unit. Lack of support from health professionals and having to face personal limits were found to accelerate the decision to admit a patient. The role of a support person involved with the caregiver was also considered and found to be an area worthy of further investigation. Health professionals must provide information and support tailored to the caregivers' needs as they change along a patient's illness trajectory.

PMID: 15126958 [PubMed - indexed for MEDLINE]

49: Int J Palliat Nurs. 2004 Mar;10(3):124-30.

Discharging patients from hospice to nursing home: a retrospective case note review.

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This article presents a retrospective case note review of in-patients at one UK hospice considered for discharge to nursing homes during 1999 and 2000. The idea of a nursing home placement was introduced, on average, around 9 days after

admission to the hospice; the most common reason cited being the inability to cope at home. Nearly a third of the patients expressed negative or ambivalent feelings about the idea. Transferring patients from hospice to nursing home is often necessary to avoid pressures on hospice beds. The potential distress of transferring patients, particularly when nearing the end of life, must be balanced against the needs of patients on hospice waiting lists. Of the 41 cases reviewed, 16 were transferred to nursing homes as planned, with a mean length of stay of just over 8 weeks. The current provision of palliative care in nursing homes raises ethical questions about transferring patients to an unfamiliar environment that may not necessarily be able to offer the same quality of palliative care. Clear communication with patients and their families and a consistent process are important to reduce some of the distress associated with this issue.

PMID: 15126956 [PubMed - indexed for MEDLINE]

50: Int J Palliat Nurs. 2004 Mar;10(3):123.

Comment in:

Int J Palliat Nurs. 2004 Mar;10(3):108.

NICE supportive and palliative care guidance.

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PMID: 15126955 [PubMed - indexed for MEDLINE]

51: Int Urol Nephrol. 2003;35(4):565-8.

Advance care planning in elderly chronic dialysis patients.

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Despite the usefulness of advance directives, most dialysis patients do not complete them. Current views of the advance care planning process emphasize that development of a specific written advance directive is only one small part of the process. Patients and families use advance care planning discussions to plan for death, achieve control over their health care, and strengthen relationships. Studies of chronic dialysis patients have shown that discussions about end-of-life care occur within the patient-family and not the patient-physician relationship. Successful advance care planning requires that dialysis care providers incorporate end-of-life care wishes and palliative care into the overall health care plans for their patients. This review focuses on the past impediments to achieving useful advance directives among dialysis patients and their families and provides some suggestions to improving this important aspect of dialysis patient care.

PMID: 15198168 [PubMed - in process]

52: J Adv Nurs. 2004 May; 46(4): 350-7.

Comment in:

J Adv Nurs. 2004 May; 46(4): 345.

Consequences count: against absolutism at the end of life.

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BACKGROUND: There has been a considerable amount of debate in the nursing literature about euthanasia, and especially the distinctions between acts and omissions, and killing and letting die. These distinctions are required by opponents of euthanasia to justify allowing some cases of passive euthanasia while forbidding all cases of active euthanasia. **AIM:** This paper adds to the debate by arguing that the position that absolutely forbids euthanasia is theoretically inconsistent. **METHODS:** The paper first considers the place of moral theory in analysing moral problems, within the framework of the principles of biomedical ethics. It is argued that despite a moral pluralism that operates in many areas, the legal status of euthanasia is based upon an absolute deontological position against deliberate killing, which cannot be overridden by appeals to favourable consequences. In order that certain forms of passive euthanasia can be allowed, this position allows distinctions within three pairs of concepts--acts and omissions, killing and letting die, and ordinary and extraordinary means. A further method of justifying certain actions near the end of life is the doctrine of double effect. These paired concepts and the doctrine of double effect are analysed with special reference to their consequences. **CONCLUSION:** The application of the doctrine of double effect and the three distinctions relies on consideration of their consequences, allowing in practice what in theory is denied. This is important because it weakens the absolute case against euthanasia, which disallows any direct consequentialist appeal. If consequences count in the application of the doctrine and the distinctions, then they should also count directly prior to their application. This strengthens the argument for active euthanasia in certain cases.

PMID: 15117346 [PubMed - indexed for MEDLINE]

53: J Adv Nurs. 2004 May; 46(4): 345.

Comment on:

J Adv Nurs. 2004 May; 46(4): 350-7.

Nurse, patient and Mr D--dancing the decision-making polka.

Mitchell K.

Publication Types:

Comment

Editorial

PMID: 15117344 [PubMed - indexed for MEDLINE]

54: J Am Geriatr Soc. 2004 Jul;52(7):1163-7.

The Personal and Social Context of Planning for End-of-Life Care.

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Objectives: To examine the potential facilitators of or deterrents to end-of-life planning for community-dwelling older adults, including personal (health-related and sociodemographic) and social (physician and family) influences. Design: In-person interviews with older adults, telephone interviews with physicians and family members. Setting: Cleveland, Ohio. Participants: Two hundred thirty-one adults aged 65 to 99 who were aging in place, 99 of their primary care physicians, and 127 of their family members. Measurements: Questions assessing older adults' discussions with others about end-of-life plans, implementation of advance directives, and physical (Older American Resources and Services) illness index and mental (Short Portable Mental Status Questionnaire) health status. Results: Just fewer than half of older adults had executed an advance directive and discussed their wishes with others. Only personal characteristics of elderly individuals were related to end-of-life plans, with whites, unmarried individuals, and younger adults more likely to have made preparations. Older adults' health status, as evaluated by the patient, physician, and caregiver, did not relate to the tendency to have made advance care plans. Older adults' family members were much more likely to report knowledge of advance care plans than were physicians. Conclusion: These findings suggest that many physicians are not talking with their patients about their end-of-life wishes. Furthermore, the propensity to have such discussions may relate more to the personal preferences and level of comfort of patients, physicians, and family members than on the health status of the older adult.

PMID: 15209656 [PubMed - in process]

55: J Am Med Dir Assoc. 2004 May-Jun;5(3):218; author reply 218.

Comment on:

J Am Med Dir Assoc. 2003 Sep-Oct;4(5):283.

Reference to preferences for cardiopulmonary resuscitation.

Iraqi A, Hughes TL.

Publication Types:

Comment

Letter

PMID: 15160730 [PubMed - indexed for MEDLINE]

56: J Am Med Dir Assoc. 2004 May-Jun;5(3):217.

Comment on:

J Am Med Dir Assoc. 2004 May-Jun;5(3):147-55.

End-of-life care in nursing homes: is the glass half empty or half full?

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Publication Types:

Comment

Editorial

PMID: 15115585 [PubMed - indexed for MEDLINE]

57: J Am Med Dir Assoc. 2004 May-Jun;5(3):197-206.

Quality palliative care in long-term care settings.

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It is paramount that physicians and midlevel practitioners who care for residents in long-term care facilities be able to provide high-quality comfort care to their patients, the majority of whom are frail and suffering from chronic and progressive diseases. Physicians must be knowledgeable in the assessment, prevention, and relief of patients' physical, emotional, and spiritual distress, as well as develop appropriate attitudes, knowledge, and skills to care for patients who are in the last years of life. The provision of high-quality palliative care is the essence of long-term care medicine.

Publication Types:

Review

Review, Tutorial

PMID: 15115582 [PubMed - indexed for MEDLINE]

58: J Am Med Dir Assoc. 2004 May-Jun;5(3):147-55.

Comment in:

J Am Med Dir Assoc. 2004 May-Jun;5(3):217.

End-of-life care in U.S. nursing homes: a review of the evidence.

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OBJECTIVES: The purpose of this study was to systematically review the empiric evidence on end-of-life care in nursing homes in the United States. The guiding research question for this review was what is the state of research evidence in end-of-life care in long-term care? **DESIGN:** We conducted a systematic review of the literature. **Data:** The review was limited to published and indexed research in peer-reviewed journals in five major databases between 1995 and October 2002. **RESULTS:** The initial search yielded a total of 395 articles. The search was narrowed, focusing on nursing homes in the United States and empiric research. The result was 43 articles related to research in end-of-life care in American nursing homes. It was categorized into eight foci: prognosis, pain, hospice, hospitalization, advanced care planning, communication, family perceptions, and miscellaneous. **CONCLUSION:** There is a dearth of research published in end-of-life care in the nursing home setting. What is available is primarily descriptive. The empiric research only documents poor end-of-life care in U.S. nursing homes. Empiric evidence has grown in this area, but there is now a need for research of creative and innovative solutions aimed at improving the quality of end-of-life care in this setting.

Publication Types:

Review

Review, Academic

PMID: 15115574 [PubMed - indexed for MEDLINE]

59: J Am Podiatr Med Assoc. 2004 Mar-Apr;94(2):198-205.

Informed consent and advance directives.

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Contrary to popular belief, a patient's signature on a piece of paper does not constitute informed consent. This article describes the ethical framework of consent in the context of the larger process of informed decision making. The elements of informed consent are examined in practical terms. Common pitfalls are addressed, with strategies to help anticipate and resolve possible dilemmas. These important tools are integral to all levels of medical decision making, including those at the end of life.

Publication Types:

Review

Review, Multicase

PMID: 15028798 [PubMed - indexed for MEDLINE]

60: J Crit Care. 2004 Jun;19(2):108-17.

A content analysis of forms, guidelines, and other materials documenting end-of-life care in intensive care units.

Clarke EB, Luce JM, Curtis JR, Danis M, Levy M, Nelson J, Solomon MZ.

Objective: The purpose of this study was to determine the extent to which data entry forms, guidelines, and other materials used for documentation in intensive care units (ICUs) attend to 6 key end-of-life care (EOLC) domains: 1) patient and family-centered decision making, 2) communication, 3) continuity of care, 4) emotional and practical support, 5) symptom management and comfort care, and 6) spiritual support. A second purpose was to determine how these materials might be modified to include more EOLC content and used to trigger clinical behaviors that might improve the quality of EOLC. **Participants:** Fifteen adult ICUs—8 medical, 2 surgical, and 4 mixed ICUs from the United States, and 1 mixed ICU in Canada, all affiliated with the Critical Care End-of-Life Peer Workgroup. **Methods:** Physician-nurse teams in each ICU received detailed checklists to facilitate and standardize collection of requested documentation materials. Content analysis was performed on the collected documents, aimed at characterizing the types of materials in use and the extent to which EOLC content was incorporated. **Measurements and main results:** The domain of symptom management and comfort care was integrated most consistently on forms and other materials across the 15 ICUs, particularly pain assessment and management. The 5 other EOLC domains of patient and family centered decision-making, communication, emotional and practical support, continuity of care, and spiritual support were not well-represented on documentation. None of the 15 ICUs supplied a comprehensive EOLC policy or EOLC critical pathway that outlined an overall, interdisciplinary, sequenced approach for the care of dying patients and their families. Nursing materials included more cues for attending to EOLC domains and were more consistently preprinted and computerized than materials used by physicians. Computerized forms concerning EOLC were uncommon. Across the 15 ICUs, there were opportunities to make EOLC-related materials more capable of triggering and documenting specific EOLC clinical behaviors. **Conclusions:** Inclusion of EOLC items on ICU formatted data entry forms and other materials capable of triggering and documenting clinician behaviors is limited, particularly for physicians. Standardized scales, protocols, and guidelines exist for many of the EOLC domains and should be evaluated for possible use in ICUs. Whether such materials can improve EOLC has yet to be determined.

PMID: 15236144 [PubMed - in process]

61: J Gen Intern Med. 2004 Feb;19(2):127-35.

Differences in Medicare expenditures during the last 3 years of life.

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OBJECTIVE: To examine age, gender, race, and area income differences in Medicare expenditures in the 3 years before death. **DESIGN:** Cross-sectional study. **PARTICIPANTS:** A random sample of aged Medicare beneficiaries who died 1996 to

1999, N = 241,047. MEASURES: We estimate differences in mean Medicare expenditures by year before death and by age, gender, race, and area income, adjusting for comorbidities and Medicaid enrollment. RESULTS: Expenditures for blacks are lower in the second and third years before death and are not significantly different from whites in the last year of life (LYOL) (y3 = 70%, P <.0001; y2 = 82%, P <.0001; LYOL = 119%, P =.098). Differences in expenditures between decedents with area incomes over \$35,000 compared to under \$20,000 attenuate by the LYOL (y3 = 116%, P <.0001; y2 = 107%, P <.0001; LYOL = 96%, P <.0001). Expenditure patterns for women versus men vary by age. Among the younger cohorts (68 to 74 and 75 to 79), expenditures are higher for women in all 3 years before death. This difference attenuates among older cohorts; in the oldest cohort (90+), expenditures for men exceed those for women by 11% in the LYOL (P <.0001). Older beneficiaries have higher expenditures in the second and third years before death but lower expenditures in the LYOL. On average, the youngest cohort expended \$8,017 more in the LYOL relative to the oldest cohort, whereas in the third year before death, the oldest cohort's expenditures were \$5,270 more than those for the youngest cohort (P <.0001). CONCLUSIONS: Age-associated differences in aggregate Medicare payments for end-of-life care are more substantial than other differences. The fact that other differences attenuate in the LYOL may reflect having overcome barriers to health care, or reflect an effective ceiling on the opportunities to provide services for persons with overwhelming illness.

PMID: 15009792 [PubMed - indexed for MEDLINE]

62: J Health Econ. 2004 Jan;23(1):111-27.

Advance directives and medical treatment at the end of life.

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To assess the consequences of advance medical directives--which explicitly specify a patient's preferences for one or more specific types of medical treatment in the event of a loss of competence--we analyze the medical care of elderly Medicare beneficiaries who died between 1985 and 1995. We compare the care of patients from states that adopted laws enhancing incentives for compliance with advance directives and laws requiring the appointment of a health care surrogate in the absence of an advance directive to the care of patients from states that did not. We report three key findings. First, laws enhancing incentives for compliance significantly reduce the probability of dying in an acute care hospital. Second, laws requiring the appointment of a surrogate significantly increase the probability of receiving acute care in the last month of life, but decrease the probability of receiving nonacute care. Third, neither type of law leads to any savings in medical expenditures.

Publication Types:
Evaluation Studies

PMID: 15154690 [PubMed - indexed for MEDLINE]

63: J Interprof Care. 2004 May; 18(2): 200-1.

Developing methods to improve the quality of end-of-life care.

Hughes R, Addington-Hall J, Aspinal F, Dunckley M, Higginson I.

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rhidian.hughes@ukonline.co.uk

PMID: 15203679 [PubMed - in process]

64: J Med Ethics. 2004 Apr; 30(2): 212-7.

Facing requests for euthanasia: a clinical practice guideline.

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On 23 September 2002, the Belgian law on euthanasia came into force. This makes Belgium the second country in the world (after the Netherlands) to have an Act on euthanasia. Even though there is currently legal regulation of euthanasia in Belgium, very little is known about how this legal regulation could be translated into care for patients who request euthanasia.

PMID: 15082821 [PubMed - indexed for MEDLINE]

65: J Nurs Law. 2003 Dec; 9(2): 29-42.

Living with AIDS: ethical problems involving death.

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PMID: 15072068 [PubMed - indexed for MEDLINE]

66: J Nurses Staff Dev. 2004 May-Jun; 20(3): 116-117.

Teaching Symptom Management in End-of-Life Care: The Didactic Content and Teaching Strategies of the End-of-Life Nursing Education Curriculum.

&NA; .

PMID: 15201830 [PubMed - as supplied by publisher]

67: J Nurses Staff Dev. 2004 May-Jun;20(3):103-15; quiz 116-7.

Teaching symptom management in end-of-life care: the didactic content and teaching strategies based on the end-of-life nursing education curriculum.

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Relief of symptoms for patients and families throughout the illness trajectory requires that palliative care practitioners have knowledge and skill, both in assessment and use of pharmacologic and complementary therapies. This article presents the didactic content of symptom assessment and management, and the experiential experiences used in a nondrug laboratory within the End-of-Life Nursing Education Consortium (ELNEC) curriculum.

PMID: 15201829 [PubMed - in process]

68: J Nurses Staff Dev. 2004 Mar-Apr;20(2):59-66; quiz 67-8.

Ethical and legal issues in end-of-life care: content of the End-of-Life Nursing Education Consortium curriculum and teaching strategies.

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The End-of-Life Nursing Education Consortium (ELNEC) is a train-the-trainer educational program to help nursing faculty integrate care of dying patients and their families in the nursing curriculum. This article presents techniques derived from the ELNEC project regarding teaching the ethics module and the key content areas for developing ethical decision-making skills in end-of-life care. Competent end-of-life nursing care begins with an understanding of ethics and the potential affect on care of dying patients and their families.

Publication Types:

Review
Review, Tutorial

PMID: 15071336 [PubMed - indexed for MEDLINE]

69: J Pain Palliat Care Pharmacother. 2004;18(1):87-109.

Comment in:

J Pain Palliat Care Pharmacother. 2004;18(1):1-2.

Advance care planning: preferences for care at the end of life.

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Predictors of patient wishes and influence of family and clinicians are discussed. Research findings on patient decision-making relating to preferences in end-of-life care are described. Advance directives and durable powers of attorney are defined and differentiated. Most patients have not participated in advance care planning and the need for more effective planning is documented. Appropriate times for discussions of such planning are described. Scenarios discussed include terminal cancer, chronic obstructive pulmonary disease, AIDS, stroke, and dementia. Patient satisfaction is discussed, as is a structured process for discussions about patient preferences. Results of patient responses to hypothetical scenarios are described. Invasiveness of interventions, prognosis and other factors that favor or discourage patient preferences for treatment are discussed. Findings resulting from research funded by the Agency for Healthcare Research and Quality (AHRQ) are discussed. This research can help providers offer end-of-life care based on preferences held by the majority of patients under similar circumstances.

Publication Types:

Review

Review, Tutorial

PMID: 15148012 [PubMed - indexed for MEDLINE]

70: J Pain Palliat Care Pharmacother. 2004;18(1):71-8.

The ethics of end-of-life research.

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A notable and welcome increase in palliative care research has led to a multitude of ethical issues and concerns for researchers, clinicians, patients (subjects) and their family members (who also might be subjects), granting agencies, and professional journals. This edition of "Palliative Care Pearls" summarizes the recommendations from a work group that met at the National Institutes of Health in September, 2002. The primary purpose for that meeting was to explore the unique characteristics of this research population and the ethical concerns that might require tailoring of "standard" clinical research processes. The proceedings culminated in a document from which open discourse and a more formal set of guidelines might emanate to both foster more and better research, while providing protections for research subjects. This 62 page long monograph was published as a supplement to the Journal of Pain and Symptom Management (April, 2003). It includes six "plenary" papers, each that focuses on a distinct ethical domain of palliative care research and concludes with a set of recommendations and research questions. These might best be viewed as hypotheses that need to be tested or further explored.

Publication Types:

Consensus Development Conference

Consensus Development Conference, NIH

Library Program Office
Office of Information
Veterans Health Administration

Review

PMID: 15148010 [PubMed - indexed for MEDLINE]

71: J Pain Palliat Care Pharmacother. 2004;18(1):5-30.

Treatment of terminal restlessness: a review of the evidence.

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Terminal restlessness is an important issue in the management of symptoms at the end of life with between 25% and 88% of dying patients exhibiting this condition. (1-5) The purpose of this review was to examine the empiric evidence about the pharmacological treatment for terminal restlessness. All available literature, in all languages, from 1966-2002 including randomized trials, concurrent observations, retrospective chart reviews, single case studies, clinical practice guidelines, expert consensus, single expert opinion articles, and editorials were reviewed as "best available evidence." Of the 72 articles reviewed, 14 met the criteria and were chosen for analysis. Despite the majority of authors recommending neuroleptic medications as a first or second line pharmacological treatment of restlessness, a number of studies demonstrated the effectiveness of other medications such as benzodiazepines (notably midazolam and lorazepam), or phenothiazines, either alone or in combinations. There is insufficient evidence to suggest that a single medication or class of medications is appropriate for terminal restlessness. There is a clear need for additional trials of neuroleptics, benzodiazepines, barbiturates, and combination protocols to determine which protocols are the most effective and have the least side effects.

Publication Types:

Review

Review, Tutorial

PMID: 15148006 [PubMed - indexed for MEDLINE]

72: J Pain Symptom Manage. 2004 May;27(5):417-24.

Cancer patient compliance in the self-administration of a pain assessment tool.

Caraceni A, Galbiati A, Brunelli C, Gorni G, Martini C, Zecca E, De Conno F.

Rehabilitation and Palliative Care Unit, National Cancer Institute of Milan, Milan, Italy.

Accurate pain assessment is considered essential for effective management of cancer pain. The aim of this study was to evaluate the compliance of hospitalized patients with chronic cancer pain, referred to an inpatient palliative care consultation service, with self-assessment of pain intensity by means of a daily pain form. The form was distributed daily by the pain consult

nurse and required three daily pain intensity measurements on 0 to 10 numerical scales, separately for pain at rest and pain on movement. Of 174 consecutive patients, 106 (61%) participated in the study and were followed up for a median of 10.6 days (range 1-32 days). Compliance was defined as the number of assessment forms completed over the number of evaluation days available for each patient. Mean compliance was 58%. The main reasons for not completing the form were related to subjective psychological variables (44%), physical distress (26%), and absence of pain (16%). Lack of understanding of the method was reported as the main reason for non-compliance by only 1% of patients.

Publication Types:
Clinical Trial

PMID: 15120770 [PubMed - indexed for MEDLINE]

73: J Pain Symptom Manage. 2004 May;27(5):392-3; author reply 393.

Comment on:
J Pain Symptom Manage. 2003 Dec;26(6):1132-9.

Re: Anemia at the end of life.

Davis MP.

Publication Types:
Comment
Letter

PMID: 15120765 [PubMed - indexed for MEDLINE]

74: J Pain Symptom Manage. 2004 May;27(5):388-90.

Chlorpheniramine maleate as an alternative to antiemetic cyclizine.

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

Publication Types:
Case Reports
Letter

PMID: 15120762 [PubMed - indexed for MEDLINE]

75: J Pain Symptom Manage. 2004 Feb;27(2):125-32.

End-of-life care in urban areas of China: a survey of 60 oncology clinicians.

Wang XS, Di LJ, Reyes-Gibby CC, Guo H, Liu SJ, Cleeland CS.

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Library Program Office
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Although cancer is a leading cause of death, little is known about cancer-related end-of-life care in China. We surveyed 60 Chinese oncology clinicians' practices and attitudes toward end-of-life care. Fewer than half reported available hospital-based hospice service, although most urban cancer patients die in the hospital. Most clinicians reported they felt competent to care for dying patients--more competent in controlling pain, constipation, nausea, and vomiting, but less competent in managing depression, anorexia, and dyspnea. Regarding disclosure, most believed that patients should know and want to know their diagnosis and stage, whereas families strongly resist informing patients. Unrealistic family expectations, fears of depressing patients, and physician reluctance to stop treatment were barriers to disclosing prognosis to patients, to ending anti-cancer therapy, and to starting palliative care. Results of the survey suggest specific training and research in symptom management that might improve end-of-life care for Chinese cancer patients.

PMID: 15157036 [PubMed - indexed for MEDLINE]

76: J Pain Symptom Manage. 2004 Feb;27(2):114-24.

Barriers to caregiver administration of pain medication in hospice care.

Letizia M, Creech S, Norton E, Shanahan M, Hedges L.

School of Nursing, Loyola University School of Nursing, Maywood, Illinois 60153, USA.

Barriers to adequate pain management in hospice and palliative care settings are an important area of investigation. In this study, a Caregiver Pain Medicine Questionnaire (CPMQ) was developed and psychometrically tested. The CPMQ is a 22-item self-report instrument that measures concern about reporting pain, concern about administering analgesics, and difficulty administering analgesics. One hundred fifty-one caregivers of patients admitted to three Chicagoland hospice agencies participated; these individuals were family members, hired caregivers in the home, or staff nurses in skilled care facilities. While only a small percentage of the caregivers expressed concern about communicating information about the patient's pain, more than a quarter were concerned about addiction, tolerance, and side effects from medications. A fourth of the caregivers had difficulty administering medications because of fear of doing something wrong and difficulty deciding which or what amount of medications to give. Male caregivers and hired caregivers had greater concerns, both about reporting information about the patient's pain and administering medications. Greater concerns were also evident among less educated caregivers, caregivers who worked in blue-collar jobs, and caregivers who were homemakers or retired. Concerns of caregivers in the home were significantly greater than staff nurse caregivers in skilled care facilities only in the belief that pain could not be controlled and concern about addiction. Caregivers who had greater concern about addiction and tolerance, and more difficulty administering medications, rated the patient's pain as less completely controlled. These findings remind hospice staff members of the importance of assessing specific caregiver concerns about medication administration and devising appropriate strategies to address them.

PMID: 15157035 [PubMed - indexed for MEDLINE]

77: J Pain Symptom Manage. 2004 Feb;27(2):98-9.

Family-perceived distress about appetite loss and bronchial secretion in the terminal phase.

Morita T, Hirai K, Sakaguchi Y, Tsuneto S, Shima Y.

Publication Types:
Evaluation Studies
Letter

PMID: 15157031 [PubMed - indexed for MEDLINE]

78: J Palliat Care. 2004 Spring;20(1):38-43.

Factors associated with caregiver burden among caregivers of terminally ill patients with cancer.

Goldstein NE, Concato J, Fried TR, Kasl SV, Johnson-Hurzeler R, Bradley EH.

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OBJECTIVE: To identify factors associated with caregiver burden among those caring for terminally ill patients with cancer. DESIGN: Cross-sectional study of interviews with primary caregivers (n = 206) of consecutive patients with cancer enrolled in the largest hospice in Connecticut. METHODS: Data were collected on the caregivers' sociodemographic characteristics, social network index, and number of restrictions in their own activities due to their caregiving role. The outcome was a nine-item questionnaire adapted from the Zarit Burden Inventory. RESULTS: The highest burden was reported among caregivers with more limited social networks (OR 1.38, CI 1.02-1.87), more restrictions in their daily activities (OR 1.35, CI 1.13-1.61), and who were younger (OR 1.46, CI 1.10-1.93). CONCLUSIONS: Variations exist in the intensity of caregiver burden based on subjective experiences and social support, rather than on the amount of assistance provided. Clinicians should consider factors such as these when targeting caregivers for interventions to alleviate burden.

PMID: 15132075 [PubMed - indexed for MEDLINE]

79: J Palliat Care. 2004 Spring;20(1):20-7.

Family perceptions of worry, symptoms, and suffering in the dying.

Hickman SE, Tilden VP, Tolle SW.

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In this exploratory study, family members of 63 decedents were interviewed by telephone, two to five months post-death, about their perceptions of their loved one's worries, symptoms, and suffering at the end of life. The most common worries reported focused on loss of bodily function (44%), being dependent (40%), and being a burden (39%). Distressing physical and psychological symptoms were reported. A majority (94%) of family members reported that their loved one suffered at the end of life, but only worries about loss of quality of life (e.g., being unable to participate in enjoyable activities) were predictive of reports of suffering. Findings suggest that worries, irrespective of the level of current symptoms, play an important role in the suffering of dying patients, and that treatment plans for the terminally ill should routinely explore both symptoms and worries.

PMID: 15132072 [PubMed - indexed for MEDLINE]

80: J Palliat Care. 2004 Spring;20(1):7-11.

The nature of suffering and its relief in the terminally ill: a qualitative study.

Daneault S, Lussier V, Mongeau S, Paille P, Hudon E, Dion D, Yelle L.

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The essential mandate of medicine is the relief of suffering. However, the quest for an integrated model towards a conceptualization of suffering is still ongoing and empirical studies are few. Qualitative inquiry using 31 in-depth interviews and content analysis was carried out between 1999 and 2001 in 26 patients diagnosed with terminal cancer. The suffering experience was described through a multiplicity of heterogeneous elements from the physical, psychological, and social spheres. Systematic synthesis of interview material yielded three apparently irreducible core dimensions. Respondents defined their suffering in terms of 1) being subjected to violence, 2) being deprived and/or overwhelmed, and 3) living in apprehension. Cassell wrote, in 1991, that to know the suffering of others demands an exhaustive understanding of what makes them the individuals they are (1). Our model can be of use in structuring and eliciting this necessary information. Understanding how a particular patient feels harmed, deprived or overburdened, and overtaken by fear, provides a lever for action tailored to the specifics of that person's experience.

PMID: 15132070 [PubMed - indexed for MEDLINE]

81: J Palliat Care. 2004 Spring;20(1):5-6.

The Canadian Virtual Hospice <www.virtualhospice.ca>.

Chochinov HM, Stern A.

Publication Types:
Editorial

PMID: 15132069 [PubMed - indexed for MEDLINE]

82: Lancet. 2004 Jun 12;363(9425):1963.

Dutch regulations governing euthanasia debated.

van Kolschooten F.

Publication Types:
News

PMID: 15195669 [PubMed - indexed for MEDLINE]

83: Lancet. 2004 Jun 5;363(9424):1877.

Oregon court upholds assisted-suicide law.

Nelson R.

Publication Types:
News

PMID: 15185700 [PubMed - indexed for MEDLINE]

84: Med Econ. 2004 Apr 9;81(7):27-30.

How to discuss end-of-life care. Here's a guide to making advance care planning a part of your practice.

Guglielmo WJ.

PMID: 15124296 [PubMed - indexed for MEDLINE]

85: Med Sci Law. 2004 Apr;44(2):182-3.

Law and science. Public law. Human rights.

[No authors listed]

Publication Types:
Legal Cases

PMID: 15212047 [PubMed - indexed for MEDLINE]

86: Nurs Crit Care. 2004 May-Jun;9(3):115-22.

'Do not attempt resuscitation' decision-making: a study exploring the attitudes and experiences of nurses.

Giles H, Moule P.

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At the time of the research being undertaken, a policy regarding resuscitation decisions did not exist at a local hospital. However, it was proposed that a new 'do not attempt resuscitation' policy should be implemented. Nurses' attitudes to, and experiences of, the communication involved in 'do not attempt resuscitation' decision-making were explored and compared with five variables (nurses' age, nurses' grade, years of nursing, area of nursing practice and length of nursing experience on current ward). Seventy-eight qualified nurses, who made up a convenience sample, participated in the study. An adapted questionnaire was used to explore nurses' attitudes to, and experiences of, 'do not attempt resuscitation' decision-making. The findings suggested that nurses' attitudes did generally concur with the guidelines outlined in the new policy. However, in practice, there were many disparities between nurses' experiences of current 'do not attempt resuscitation' decision-making and the policy's guidelines. There were no significant differences between nurses' attitudes to current 'do not attempt resuscitation' decision-making and the five variables. However, there was one significant difference identified between nurses' experiences and the area of nursing practice ($p=0.008$). To adhere to the principles of the forthcoming 'do not attempt resuscitation' policy at the local hospital, the research findings have suggested that changes need to occur to both nurses' attitudes to and nurses' experiences of current 'do not attempt resuscitation' decision-making.

PMID: 15152753 [PubMed - indexed for MEDLINE]

87: Nurs Manage. 2001 Oct;32(10):32-5.

Enhance end-of-life care.

Childress SB.

VA Medical Center, Salt Lake City, Utah, USA.

A university-based veteran's medical center targets caregiver communication and patient feedback as the foundation of its end-of-life care quality improvement initiative.

PMID: 15129494 [PubMed - indexed for MEDLINE]

88: Nurs Times. 2004 May 4-10;100(18):56-9.

Legal issues concerning the withholding of feeding from patients.

Dimond B.

University of Glamorgan.

The law surrounding the withholding or withdrawal of feeding from patients is complex and dependent upon case law (also known as common law or judge-made law). There are no statutory provisions and the leading case in this area is the Tony Bland case (Alredale NHS Trust v Bland, 1993).

Publication Types:

- Legal Cases
- Review
- Review, Tutorial

PMID: 15151010 [PubMed - indexed for MEDLINE]

89: Nursing. 2004 Mar;34(3):46-7.

Mr. Sam's visitor.

Bottoms SM.

Maury Regional Hospital in Columbia, Tenn, USA.

PMID: 15180003 [PubMed - indexed for MEDLINE]

90: Omega (Westport). 2002-2003;46(2):105-15.

Attitudes toward physician assisted suicide: Poland and the United States.

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A scale to measure attitudes toward physician assisted suicide was administered to a sample (N=246) of Polish citizens and a sample (N=246) of U.S. citizens equated on gender, marital status, religion, and socioeconomic level. In both samples the reliability was substantial (Cronbach's alphas of .93 and .89), and the factor structure identical (one major factor). Significant ethnic differences were found for 10 of the 12 scale items, but no differences related to demographic variables. The obtained differences appear to parallel a conservative-liberal dimension, though this will need to be assessed in future studies.

PMID: 15080104 [PubMed - indexed for MEDLINE]

91: Omega (Westport). 2002-2003;46(3):199-214.

Community attitudes toward physician assisted suicide.

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Attitudes toward physician-assisted suicide (PAS) were assessed in a sample of 400 community adults, stratified as to gender and socioeconomic class, using a 12-item psychometric scale rather than the more typical survey question. The results indicate that the Domino scale, currently the only psychometric instrument of attitudes toward PAS, is factorially homogeneous and shows considerable internal stability. There were no gender differences, but significant socioeconomic class differences were obtained with better educated, upper class individuals more favorable in attitude than semi-skilled and unskilled poorly educated lower social class individuals. The majority of respondents support physician assisted suicide, but such support is inversely related to age.

PMID: 15072085 [PubMed - indexed for MEDLINE]

92: *Onkologie*. 2004 Apr;27(2):138-42.

Palliative care in Kerala, India: a model for resource-poor settings.

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BACKGROUND: The need for palliative care is increasing throughout the world. Developing countries are progressively faced with an ageing population, whose changing health needs require urgent action. Insufficient access to care for both cancer and AIDS patients make palliative care the only humane and feasible response in many contexts. **MATERIAL AND METHODS:** In order to describe the need for palliative care in Kerala and the development of the new palliative care policy, we have collected and reviewed information from government officials, health professionals involved in cancer care, patients and their families, sponsors, and members of palliative care teams across Kerala. We also collected data on the functioning of the newly established palliative care clinics. **RESULTS:** The Pain and Palliative Care Society developed in a few years a network of 33 palliative care clinics across Kerala, providing care free of charge to patients in need. Outpatient treatment with a supportive home care service was adopted as the main mode of operation. Trained volunteers from the community assisted in providing care, and family members were empowered to the highest degree in order to ensure continuity of treatment. In 2002 the network of clinics saw about 6,000 new patients, about 25% of incident cancer cases. **CONCLUSIONS:** The synergistic effect of motivation and knowledge, coupled with the use of local resources, has made possible the development of a network of palliative care services, available for free to terminally ill patients. The challenge of adapting such a model to other developing countries is discussed. Copyright 2004 S. Karger GmbH, Freiburg

PMID: 15138345 [PubMed - indexed for MEDLINE]

93: *Palliat Med*. 2004 Apr;18(3):202-16.

The quality of medical care at the end-of-life in the USA: existing barriers and examples of process and outcome measures.

Yabroff KR, Mandelblatt JS, Ingham J.

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CONTEXT: Cancer is a leading cause of morbidity and mortality in the USA and despite many recent advances in detection and treatment, over half a million cancer patients in this country will die from their disease each year. OBJECTIVE: Using cancer as a prototype, we provide a conceptual framework to identify and review barriers to optimal end-of-life care and propose examples of linked process and outcome measures that could be used to evaluate whether standards of optimal end-of-life care are being achieved. METHODS: We propose a conceptual model of end-of-life care and use this model to review the published literature to identify the key goals of optimal end-of-life care and summarize existing barriers to optimal end-of-life care. We then provide examples of process and outcome measures linked to the goals of optimal end-of-life care and domains within the conceptual framework. RESULTS: Within all components of care at the end-of-life--societal attitudes, health care system(s), providers, and patients and their families--there are significant barriers to the quality of care. Some of the most critical barriers to optimal care at the end-of-life in the USA are limited availability, and coverage of, co-ordinated service delivery; poor provider communication and diagnostic skills; limited opportunities for training in palliative care; patient fears and attitudes towards the sick role, and a lack of, or inadequate health insurance. Proposed patient, provider, and system level measures of the quality of care were guided by goals of optimal end-of-life care, and focus on communication about prognosis and risks and benefits of treatment, development of clear and informed treatment goals, delivery of services consistent with treatment goals, and promotion of quality of life. CONCLUSIONS: At present, there are substantial societal, health care system, provider, and patient barriers to obtaining optimal cancer care at the end-of-life. Ongoing discussions about appropriate measures of the quality of end-of-life care are gaining momentum, however. The proposed process and outcome measures for assessing optimal end-of-life care use cancer as a prototype, but are broadly applicable to other patient populations with life-threatening disease.

PMID: 15198133 [PubMed - in process]

94: Palliat Med. 2004 Apr; 18(3): 184-94.

Delirium in advanced cancer patients.

Centeno C, Sanz A, Bruera E.

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Delirium in advanced cancer is often poorly identified and inappropriately managed. It is one of the most common causes for admission to clinical institutions and is the most frequently cited psychiatric disorder in terminal cancer. Diagnosis of delirium is defined as a disturbance of consciousness and

attention with a change in cognition and/or perception. In addition, it develops suddenly and follows a fluctuating course and it is related to other causes, such as cancer, metabolic disorders or the effects of drugs. Delirium occurs in 26% to 44% of cancer patients admitted to hospital or hospice. Of all advanced cancer patients, over 80% eventually experience delirium in their final days. In advanced cancer, delirium is a multifactorial syndrome where opioids factor in almost 60% of episodes. Delirium in such patients, excluding terminal delirium, may be reversible in 50% of cases. Providing adequate end-of-life care for a patient with delirium is the main challenge. The family needs advice and it is important to create a relaxing environment for the patient. The primary therapeutic approach is to identify the reversible causes of delirium. Some therapeutic strategies have been shown to be effective: reduction or withdrawal of the psychoactive medication, opioid rotation, and hydration. Haloperidol is the most frequently used drug, and new neuroleptics such as risperidone or olanzapine are being tested with good results. Methylphenidate has been used for hypoactive delirium.

PMID: 15198131 [PubMed - in process]

95: Psychol Rep. 2004 Apr;94(2):637-48.

Loneliness in cancer and multiple sclerosis patients.

Rokach A.

Loneliness is a universal social phenomenon often producing debilitating effects on many aspects of human functioning. The present study compared the qualitative aspects of loneliness in two terminally ill samples to that of a more healthy sample. 329 multiple sclerosis and 315 cancer patients, as well as 391 nonrandom healthy participants answered a 30-item questionnaire on loneliness. Analysis indicated the experience of loneliness which characterizes multiple sclerosis and cancer patients differs from that of the more healthy group.

PMID: 15154196 [PubMed - indexed for MEDLINE]

96: Rep Med Guidel Outcomes Res. 2004 Apr 30;15(9):1-2, 5.

End-of-life care varies significantly even among top hospitals.

Rollins G.

Publication Types:

News

PMID: 15146845 [PubMed - indexed for MEDLINE]

97: Swiss Med Wkly. 2004 Feb 7;134(5-6):65-8.

Ethical principles in end-of-life decisions in different European countries.

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The majority of ICU deaths are preceded by a decision to limit treatment in some way. Decisions to withhold or withdraw treatment vary considerably depending on many factors including local practice, cultural and religious background, family and peer pressure. Here we will discuss the current situation across Europe, based on the findings from three large international studies.

Publication Types:

Review

Review, Tutorial

PMID: 15113053 [PubMed - indexed for MEDLINE]

98: Telemed J E Health. 2004 Spring;10(1):103-7.

Using telehealth technology to support CME in end-of-life care for community physicians in Ontario.

Lynch J, Weaver L, Hall P, Langlois S, Stunt M, Schroder C, Bouvette M.

SCO Health Service, Ottawa, Ontario, Canada. jglynch@scohs.on.ca

Publication Types:

Evaluation Studies

PMID: 15104922 [PubMed - indexed for MEDLINE]

99: Theor Med Bioeth. 2004;25(1):61-74.

The double life of double effect.

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The U.S. Supreme Court's majority opinion in *Vacco v. Quill* assumes that the principle of double effect explains the permissibility of hastening death in the context of ordinary palliative care and in extraordinary cases in which painkilling drugs have failed to relieve especially intractable suffering and terminal sedation has been adopted as a last resort. The traditional doctrine of double effect, understood as providing a prohibition on instrumental harming as opposed to incidental harming or harming as a side effect, must be distinguished from other ways in which the claim that a result is not intended might be offered as part of a justification for it. Although double effect might appropriately be invoked as a constraint on ordinary palliative care, it is not clear that it can be coherently extended to justify such practices as terminal sedation. A better approach would reconsider double effect's traditional

prohibition on hastening death as a means to relieve suffering in the context of acute palliative care.

Publication Types:
Legal Cases

PMID: 15180096 [PubMed - indexed for MEDLINE]

100: Theor Med Bioeth. 2004;25(1):51-60.

Medical ethics and double effect: the case of terminal sedation.

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The use of terminal sedation to control the intense discomfort of dying patients appears both to be an established practice in palliative care and to run counter to the moral and legal norm that forbids health care professionals from intentionally killing patients. This raises the worry that the requirements of established palliative care are incompatible with moral and legal opposition to euthanasia. This paper explains how the doctrine of double effect can be relied on to distinguish terminal sedation from euthanasia. The doctrine of double effect is rooted in Catholic moral casuistry, but its application in law and morality need not depend on the particular framework in which it was developed. The paper further explains how the moral weight of the distinction between intended harms and merely foreseen harms in the doctrine of double effect can be justified by appeal to a limitation on the human capacity to pursue good.

PMID: 15180095 [PubMed - indexed for MEDLINE]