



END OF LIFE CARE BIBLIOGRAPHY April 2004

1: Age Ageing. 2003 Jul; 32(4):445-9.

Hospitalisation, care plans and not for resuscitation orders in older people in the last year of life.

Chan DK, Ong B, Zhang K, Li R, Liu JG, Iedema R, Braithwaite J.

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BACKGROUND: over 60% of older people have at least one admission to hospital in their last year of life, with the majority of people having multiple admissions. In Bankstown, New South Wales, Australia, we have a diverse ethnic and cultural population. We were interested in bed utilisation, documentation, and follow through of "care plans" as well as "not for resuscitation" orders in the last year of life of the older people in our area. **METHODS:** we reviewed and collected data from the medical records of patients over 65 years of age who died in our hospital. Reviewers included a medical registrar, a research officer and two geriatricians. We collected a wide range of information pertaining to the 12 months before death. This included demographics, chronic illnesses, geriatric syndromes, number of admissions, bed days, care plans, and not for resuscitation orders as well as other relevant data. **RESULTS:** 110 patients' records were reviewed. The mean age was 80 years and 31% were from a non English-speaking background. The average number of admissions was 2.4 and the average number of bed days in the last year of life was 25. Sixty-one of the patients had a care plan and a not for resuscitation order, 91% of which were written shortly before death. Using bi-variate analysis of old age (over 80), number of chronic illnesses, or geriatric syndromes present, the number of bed days was positively correlated to care plan and not for resuscitation orders. Logistic multivariate analysis of chronic illnesses revealed that stroke ($P=0.024$) as well as stroke and fracture ($P=0.008$) were strongly correlated with care plan and not for resuscitation orders. Only 8 patients had an advanced care plan documented prior to last admission. When advanced care plans were documented, they were generally clearly written and followed through appropriately (7 out of 8). **CONCLUSION:** this study showed that in our diverse population there were multiple admissions and utilisation of hospital beds for older people in their last year of life. Care plans and not for resuscitation orders were rarely documented prior to last admission. However, when advanced care plans were done, they were usually well documented and followed through appropriately.

PMID: 12851192 [PubMed - indexed for MEDLINE]

2: Am J Hosp Palliat Care. 2004 Mar-Apr; 21(2): 116-20.

Dying with dignity: the good patient versus the good death.

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Death is a unique experience for each human being, yet there is tremendous societal pressure on a dying person to be a "good patient" while trying to experience the "good death." These pressures shape patient, caregiver, and family choices in end-of-life situations. The purpose of this literature review was twofold: first, to develop an understanding of "dying with dignity" to enhance the end-of-life care received by dying patients, and second, to contribute to a concept analysis of dignity to improve the clarity and consistency of future research related to dignity in aging individuals. Articles pertaining to dying with dignity from the disciplines of nursing, medicine, ethics, psychology, and sociology were reviewed using a matrix method. A dichotomy surrounding dying with dignity emerged from this review. The definition of dignity in dying identifies not only an intrinsic, unconditional quality of human worth, but also the external qualities of physical comfort, autonomy, meaningfulness, usefulness, preparedness, and interpersonal connection. For many elderly individuals, death is a process, rather than a moment in time, resting on a need for balance between the technology of science and the transcendence of spirituality.

PMID: 15055511 [PubMed - in process]

3: Ann Fam Med. 2004 Jan-Feb; 2(1):54-60.

The TLC model of palliative care in the elderly: preliminary application in the assisted living setting.

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Substantial shortfalls in the quality of palliative care of the elderly can be attributed to 5 fundamental flaws in the way end-of-life care is currently delivered. First, palliative care is viewed as a terminal event rather than a longitudinal process, resulting in a reactive approach and unnecessary preterminal distress in elderly patients suffering from chronic, slowly progressive illnesses. Second, palliative care is defined in terms of a false dichotomy between symptomatic and disease-focused treatment, which distracts attention from the proper focus of healing illness. Third, the decision about whether the focus of care should be palliative is not negotiated among patients, family members, and providers. Fourth, patient autonomy in making treatment choices is accorded undue prominence relative to more salient patient choices, such as coming to terms with their place in the trajectory of chronic illness. Fifth, palliative care is a parallel system rather than an integrated primary care process. A new theoretical framework--the TLC model--addresses these flaws

in the provision of palliative care for elderly persons. In this model, optimal palliative care is envisioned as timely and team oriented, longitudinal, collaborative and comprehensive. The model is informed by the chronic illness care, shared decision making, and comprehensive geriatric assessment research literature, as well as previous palliative care research. Preliminary results of an intervention for elderly assisted living residents based on the TLC model support its promise as a framework for optimizing palliative care of elders.

PMID: 15053284 [PubMed - in process]

4: Arch Intern Med. 2004 Mar 8;164(5):538-44.

Trends in postdischarge mortality and readmissions: has length of stay declined too far?

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BACKGROUND: Length of hospital stay continues to decline, but the effect on postdischarge outcomes is unclear. **METHODS:** We determined trends in risk-adjusted mortality rates and readmission rates for 83,445 Medicare patients discharged alive after hospitalization for myocardial infarction, heart failure, gastrointestinal hemorrhage, chronic obstructive pulmonary disease, pneumonia, or stroke. Patients were stratified into deciles of observed/expected length of stay to determine whether patients whose length of stay was much shorter than expected had higher risk-adjusted mortality and readmission rates. Analyses were stratified by whether a do-not-resuscitate (DNR) order was written within 2 days of admission (early) or later. **RESULTS:** From 1991 through 1997, risk-adjusted postdischarge mortality generally remained stable for patients without a DNR order. Postdischarge mortality increased by 21% to 72% for patients with early DNR orders and increased for 2 of 6 diagnoses for patients with late DNR orders. Markedly shorter than expected length of stay was associated with higher than expected risk-adjusted mortality for patients with early DNR orders but not for others (no DNR and late DNR). Risk-adjusted readmission rates remained stable from 1991 through 1997, except for a 15% (95% confidence interval, 3%-30%) increase for patients with congestive heart failure. Short observed/expected length of stay was not associated with higher readmission rates. **CONCLUSIONS:** The dramatic decline in length of stay from 1991 through 1997 was not associated with worse postdischarge outcomes for patients without DNR orders. However, postdischarge mortality increased among patients with early DNR orders, and some of this trend may be due to patients being discharged more rapidly than previously.

Publication Types:
Multicenter Study

PMID: 15006831 [PubMed - indexed for MEDLINE]

5: Arch Intern Med. 2004 Feb 9;164(3):321-6.

Dying with advanced dementia in the nursing home.

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BACKGROUND: Nursing homes are important providers of end-of-life care to persons with advanced dementia. **METHODS:** We used data from the Minimum Data Set (June 1, 1994, to December 31, 1997) to identify persons 65 years and older who died with advanced dementia (n = 1609) and terminal cancer (n = 883) within 1 year of admission to any New York State nursing home. Variables from the Minimum Data Set assessment completed within 120 days of death were used to describe and compare the end-of-life experiences of these 2 groups. **RESULTS:** At nursing home admission, only 1.1% of residents with advanced dementia were perceived to have a life expectancy of less than 6 months; however, 71.0% died within that period. Before death, 55.1% of demented residents had a do-not-resuscitate order, and 1.4% had a do-not-hospitalize order. Nonpalliative interventions were common among residents dying with advanced dementia: tube feeding, 25.0%; laboratory tests, 49.2%; restraints, 11.2%; and intravenous therapy, 10.1%. Residents with dementia were less likely than those with cancer to have directives limiting care but were more likely to experience burdensome interventions: do-not-resuscitate order (adjusted odds ratio [OR], 0.12; 95% confidence interval [CI], 0.09-0.16), do-not-hospitalize order (adjusted OR, 0.33; 95% CI, 0.16-0.66), tube feeding (adjusted OR, 2.21; 95% CI, 1.51-3.23), laboratory tests (adjusted OR, 2.53; 95% CI, 2.01-3.18), and restraints (adjusted OR, 1.79; 95% CI, 1.23-2.61). Distressing conditions common in advanced dementia included pressure ulcers (14.7%), constipation (13.7%), pain (11.5%), and shortness of breath (8.2%). **CONCLUSIONS:** Nursing home residents dying with advanced dementia are not perceived as having a terminal condition, and most do not receive optimal palliative care. Management and educational strategies are needed to improve end-of-life care in advanced dementia.

PMID: 14769629 [PubMed - indexed for MEDLINE]

6: BMJ. 2004 Mar 20;328(7441):661.

Hospital breached boy's human rights by treating him against his mother's wishes.

Dyer C.

Publication Types:
News

PMID: 15031222 [PubMed - indexed for MEDLINE]

7: BMJ. 2004 Mar 13;328(7440):607.

Comment in:

BMJ. 2004 Mar 13;328(7440):610.

Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States.

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OBJECTIVE: To evaluate the use of healthcare resources during the last six months of life among patients of US hospitals with strong reputations for high quality care in managing chronic illness. **DESIGN:** Retrospective cohort study based on claims data from the US Medicare programme. **PARTICIPANTS:** Cohorts receiving most of their hospital care from 77 hospitals that appeared on the 2001 US News and World Report "best hospitals" list for heart and pulmonary disease, cancer, and geriatric services. **MAIN OUTCOME MEASURES:** Use of healthcare resources in the last six months of life: number of days spent in hospital and in intensive care units; number of physician visits; percentage of patients seeing 10 or more physicians; percentage enrolled in hospice. Terminal care: percentage of deaths occurring in hospital; percentage of deaths occurring in association with a stay in an intensive care unit. **RESULTS:** Extensive variation in each measure existed among the 77 hospital cohorts. Days in hospital per decedent ranged from 9.4 to 27.1 (interquartile range 11.6-16.1); days in intensive care units ranged from 1.6 to 9.5 (2.6-4.5); number of physician visits ranged from 17.6 to 76.2 (25.5-39.5); percentage of patients seeing 10 or more physicians ranged from 16.9% to 58.5% (29.4-43.4%); and hospice enrollment ranged from 10.8% to 43.8% (22.0-32.0%). The percentage of deaths occurring in hospital ranged from 15.9% to 55.6% (35.4-43.1%), and the percentage of deaths associated with a stay in intensive care ranged from 8.4% to 36.8% (20.2-27.1%). **CONCLUSION:** Striking variation exists in the utilisation of end of life care among US medical centres with strong national reputations for clinical care.

PMID: 15016692 [PubMed - indexed for MEDLINE]

8: Br J Nurs. 2004 Feb 12-25;13(3):132-6, 138-9.

Integration of critical care and palliative care at end of life.

Pattison N.

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End-of-life care in the critical care environment suffers from a lack of clarity and uncertainty. Critical care nurses may often feel torn between wanting to do everything possible to sustain a patient's life and wanting to do what is in the patient's best interests. Reframing the focus of care from cure to comfort can be an uncomfortable shift for nurses, who may not be in control of when the change of goals takes place. Good end-of-life care should be a core competency for all nurses and it is our responsibility to ensure that decisions to forgo life-sustaining treatment in critical care are appropriate and timely. Futility, conflict and resources all factor in such decisions. Nurses must ensure the

transition from cure to comfort does not emphasize a dichotomy between palliative care and critical care but instead focuses on the provision of the best possible end-of-life care.

Publication Types:

Case Reports
Review
Review, Tutorial

PMID: 14997074 [PubMed - indexed for MEDLINE]

9: Br J Nurs. 2004 Feb 12-25;13(3):175.

Nurses should be more involved in DNR decisions.

Castledine G.

University of Central England, Birmingham.

PMID: 14997080 [PubMed - indexed for MEDLINE]

10: Can J Surg. 2004 Feb;47(1):8-9.

Maimonides's cooling period and organ retrieval.

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Publication Types:

Historical Article
Review
Review, Tutorial

PMID: 14997917 [PubMed - indexed for MEDLINE]

11: Cancer Invest. 2004;22(1):123-31.

Examining ethical dilemmas as obstacles to hospice and palliative care for advanced cancer patients.

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Oncologists deal almost exclusively with patients with serious and life-threatening diseases, many who are terminally ill. While hospice care

remains an ideal model of care for cancer patients with life-ending disease, many obstacles are present in the clinical setting that either impede or prevent the otherwise appropriate referral of patients eligible for this type of end-of-life care. These obstacles are best viewed as ethical dilemmas for oncology clinicians, as they often challenge or obscure a clinician's perceptions about what is in the best interests of their advanced cancer patients. These dilemmas include: Issues surrounding prognosis determination and communication, Concerns about effectively communicating a terminal prognosis while still allowing patients and families to maintain hope, Conflicts of interests for involved clinicians and, Potential problems of the current reimbursement mechanisms for hospice which may be inadequate to meet the needs of all dying cancer patients. For oncologists caring for advanced cancer patients, it is essential that they have a working knowledge regarding these ethical issues, and overt dilemmas, present in end-of-life cancer care in order that they might better appreciate how, and when, to initiate palliative and hospice care for as many of their patients as possible.

PMID: 15069770 [PubMed - in process]

12: Cancer Nurs. 2003 Dec;26(6):448-53.

Telephone support for caregivers of patients with cancer.

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Caregivers have complex needs as they care for a loved one with cancer at the end of life. The objective of this pilot study was to determine the feasibility of conducting a brief telephone intervention, Tele-Care II, for caregivers of hospice patients. Guided by Hogan's Model of Bereavement, nurse interventionists implemented Tele-Care II via teleconference calls with caregivers. Although 14 caregivers were recruited for the study, only 5 were able to complete the intervention before the patient's death. Those completing the intervention experienced decreased depression, despair, and disorganization although the patient's condition became more serious. Late enrollment in hospice continues to be problematic for patients, family caregivers, and hospice staff because it allows little time for completion of interventions with family caregivers before the patient's death.

Publication Types:
Evaluation Studies

PMID: 15022976 [PubMed - indexed for MEDLINE]

13: Caring. 2004 Jan;23(1):14-7.

International perspectives on the role of home care and hospice in aging and long-term care.

May V, Onarcan M, Olechowski C, Mayron Z.

Village Baxter, Victoria, Australia.

PMID: 14870475 [PubMed - indexed for MEDLINE]

14: Caring. 2004 Jan;23(1):22-5.

Innovative home care & hospice. Cross-partnerships in Russia & Latvia.

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Through the American International Health Alliance (AIHA), there are forty partnerships (peer-to-peer and institution-to-institution) between the U.S. and countries in Central and Eastern Europe working to advance global health through the efforts of volunteers. AIHA serves as a catalyst and broker to oversee the grants that support these partnerships and provide administration and management consistent with U.S. government regulations.

PMID: 14870477 [PubMed - indexed for MEDLINE]

15: Caring. 2004 Jan;23(1):34-6.

Development of hospice in China.

Xue Y, Milone-Nuzzo P.

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Hospice began in China with a research center founded in 1988. After a survey measured national attitudes about death, the ground was laid for the first clinical ward to be opened in October, 1990. The Chinese philosophy of hospice is consistent with the rest of the world--to provide holistic care to improve quality of life while keeping the family as the core unit of care.

PMID: 14870480 [PubMed - indexed for MEDLINE]

16: Caring. 2004 Jan;23(1):38-9.

Dealing with dying, death and grief.

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PMID: 14870481 [PubMed - indexed for MEDLINE]

17: Clin Geriatr Med. 2003 Nov;19(4):841-56, vii-viii.

End-of-life care in geriatric psychiatry.

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Depression, anxiety and delirium are relatively common during the final stages of terminal disease, and each can profoundly impact the quality of those last days for both patient and involved family. In this article the authors review the assessment and treatment of each syndrome in the context of palliative care for older adults. Treatment of mental disorders at the end of life warrants special consideration due to the need to balance the benefits of treatment against the potential burden of the intervention, especially those that might worsen quality of life. Dementia and the complications of depression and behavioral disturbance within dementia are also discussed. Finally, caregivers of dying patients are vulnerable to stress, depression, grief, and complicated bereavement. Interventions for caregivers who are debilitated by these states are briefly summarized.

PMID: 15024815 [PubMed - in process]

18: Clin Med. 2003 Sep-Oct; 3(5): 483.

Comment on:

Clin Med. 2003 Mar-Apr; 3(2): 149-52.

'If only someone had told me ...' a review of the care of patients dying in hospital.

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

Publication Types:

Comment

Letter

PMID: 14601954 [PubMed - indexed for MEDLINE]

19: Clin Med. 2003 Sep-Oct; 3(5): 416-8.

Ethical considerations in the care of older people.

Eccles J.

Elderly Medicine, St James's University Hospital, Leeds.

Publication Types:

Review

Review, Tutorial

PMID: 14601939 [PubMed - indexed for MEDLINE]

Library Program Office
Office of Information
Veterans Health Administration

20: Clin Med. 2003 Sep-Oct; 3(5): 460-3.

Medical murder by omission? The law and ethics of withholding and withdrawing treatment and tube feeding.

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When is it lawful and ethical to withhold or withdraw treatment and tube feeding? In recent years, the courts have handed down important decisions and medical bodies have issued professional guidelines on withholding and withdrawing treatment and tube feeding. A major criticism of these decisions and guidelines has been that while they prohibit the intentional hastening of a patient's life by an act ('active euthanasia'), they permit the intentional hastening of a patient's death by omission ('passive euthanasia'); and they prohibit actively assisting suicide, but permit passively assisting suicide. By focusing on the landmark decision of the Law Lords in the Tony Bland case, and on the guidelines on withholding and withdrawing treatment and tube feeding issued by the British Medical Association, this paper considers whether this criticism is sound, and concludes that it is.

Publication Types:

Review

Review, Tutorial

PMID: 14601947 [PubMed - indexed for MEDLINE]

21: Eur J Cancer Care (Engl). 2004 Mar; 13(1): 36-44.

An investigation of inpatient referrals to a clinical psychologist in a hospice.

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A clinical psychologist, in a new post in a hospice, developed an assessment, therapeutic and consultation role. A retrospective, diary-based audit was made of the inpatients referred during the first 2 years, allowing an examination of referral practices and changes over time as the psychologist's role developed. During the 2 years 11% of the hospice inpatients were referred, consistent with previous published work in this area. Referrals increased from 10% in year 1 to 12% in year 2. Referrals were not skewed in terms of patient gender or diagnosis but younger patients were referred more. Comparison with other studies suggests the psychologist's gender may influence referral rates of woman patients. Referrals for depression and anxiety increased in year 2 but decreased for pain. The number of patients seen with marital/family stresses also increased with time. Such patients required the most psychological input. Patients with problems of alcohol misuse or dementia were particularly challenging for the hospice team and specific training was developed. The psychologist's role is

discussed in the light of these findings, particularly in enhancing the multidisciplinary team's holistic approach to the patient and their family, by emphasizing the patient's experience and the collaborative basis of care.

PMID: 14961774 [PubMed - indexed for MEDLINE]

22: Geriatr Nurs. 2004 Jan-Feb;25(1):58-9.

Research guiding practice related to cultural issues at end of life care.

Goldstein C, Anapolsky E, Park J, Immordino M, Ukoha N.

University of Maryland School of Nursing in Baltimore, USA.

PMID: 14976511 [PubMed - indexed for MEDLINE]

23: Harv Womens Health Watch. 2004 Jan;11(5):7.

A doctor discusses...advance care directives.

Robb-Nicholson C.

PMID: 14738106 [PubMed - indexed for MEDLINE]

24: Harv Womens Health Watch. 2004 Jan;11(5):6-7.

Living wills and health care proxies. Documenting your health care wishes can help ensure that your voice will be heard should you be unable to speak for yourself.

[No authors listed]

PMID: 14734269 [PubMed - indexed for MEDLINE]

25: Health Aff (Millwood). 2003 Nov-Dec;22(6):239-43.

At the end of A day. A young doctor considers an end-of-life decision and the love that informs it.

Khorana A.

University of Rochester, James P Wilmot Cancer Center, USA.

PMID: 14649452 [PubMed - indexed for MEDLINE]

26: Health News. 2004 Mar;10(3):8-9.

Planning for the unexpected: do it now. Health proxies and living wills communicate your healthcare wishes if you are unable to. Yet fewer than 20 percent of Americans have such plans in place.

[No authors listed]

PMID: 15017938 [PubMed - indexed for MEDLINE]

27: Health Psychol. 2003 Nov;22(6):605-15.

Stability of older adults' preferences for life-sustaining medical treatment.

Ditto PH, Smucker WD, Danks JH, Jacobson JA, Houts RM, Fagerlin A, Coppola KM, Gready RM.

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The use of instructional advance directives assumes that preferences for life-sustaining medical treatment remain stable over time and across changes in life condition. A sample of 332 older adults recorded their preferences for 4 life-sustaining treatments in 9 illness scenarios. These preferences were elicited again 1 and 2 years after the original interview. Overall, preferences for life-sustaining treatment were moderately stable over time, but stability varied significantly across judgments. Preferences were most stable for illness scenarios that were most and least serious and for decisions to refuse treatment. Age, gender, education, and prior completion of an advance directive were all related to preference stability, and evidence indicated that declines in physical or psychological functioning resulted in decreased interest in life-sustaining treatment.

PMID: 14640858 [PubMed - indexed for MEDLINE]

28: Health Serv Res. 2004 Apr;39(2):363-75.

Trends in inpatient treatment intensity among Medicare beneficiaries at the end of life.

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OBJECTIVE: Although an increasing fraction of Medicare beneficiaries die outside the hospital, the proportion of total Medicare expenditures attributable to care in the last year of life has not dropped. We sought to determine whether disproportionate increases in hospital treatment intensity over time among decedents are responsible for the persistent growth in end-of-life expenditures. DATA SOURCE: The 1985-1999 Medicare Medical Provider Analysis and Review (MedPAR) and Denominator files. STUDY DESIGN: We sampled inpatient claims for 20

percent of all elderly fee-for-service Medicare decedents and 5 percent of all survivors between 1985 and 1999 and calculated age-, race-, and gender-adjusted per-capita inpatient expenditures and rates of intensive care unit (ICU) and intensive procedure use. We used the decedent-to-survivor expenditure ratio to determine whether growth rates among decedents outpaced growth relative to survivors, using the growth rate among survivors to control for secular trends in treatment intensity. Data Collection. The data were collected by the Centers for Medicare and Medicaid Services. PRINCIPAL FINDINGS: Real inpatient expenditures for the Medicare fee-for-service population increased by 60 percent, from \$58 billion in 1985 to \$90 billion in 1999, one-quarter of which were accrued by decedents. Between 1985 and 1999 the proportion of beneficiaries with one or more intensive care unit (ICU) admission increased from 30.5 percent to 35.0 percent among decedents and from 5.0 percent to 7.1 percent among survivors; those undergoing one or more intensive procedure increased from 20.9 percent to 31.0 percent among decedents and from 5.8 percent to 8.5 percent among survivors. The majority of intensive procedures in the United States were performed in the more numerous survivors, although in 1999 50 percent of feeding tube placements, 60 percent of intubations/tracheostomies, and 75 percent of cardiopulmonary resuscitations were in decedents. The proportion of beneficiaries dying in a hospital decreased from 44.4 percent to 39.3 percent, but the likelihood of being admitted to an ICU or undergoing an intensive procedure during the terminal hospitalization increased from 38.0 percent to 39.8 percent and from 17.8 percent to 30.3 percent, respectively. One in five Medicare beneficiaries who died in the hospital in 1999 received mechanical ventilation during their terminal admission. CONCLUSIONS: Inpatient treatment intensity for all fee-for-service beneficiaries increased between 1985 and 1999 regardless of survivorship status. Absolute changes in per-capita hospital expenditures, ICU admissions, and intensive inpatient procedure use were much higher among decedents. Relative changes were similar except for ICU admissions, which grew faster among survivors. The secular decline in in-hospital deaths has not resulted in decreased per capita utilization of expensive inpatient services in the last year of life. This could imply that net hospital expenditures for the dying might have been even higher over this time period if the shift toward hospice had not occurred.

PMID: 15032959 [PubMed - indexed for MEDLINE]

29: Health Soc Work. 2004 Feb;29(1):7-15.

Social work and end-of-life care for older people: a historical perspective.

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End-of-life issues became increasingly complicated during the 20th century as profound shifts occurred in who died, how they died, and when they died. This article reviews societal changes related to death in the United States and chronicles the developments in social work practice with and for dying people and their families in the 20th century, leading up to the 1993 policy statement of the National Association of Social Workers on end-of-life decision making, which reinforced that client self-determination, a fundamental principle of social work, should apply to people planning for their deaths or undergoing a

dying process. After identifying limitations in policies and practices, suggestions are offered to promote competent social work practice and enhance end-of-life care, particularly with reference to the dying process of older people.

PMID: 15024914 [PubMed - in process]

30: Home Healthc Nurse. 2004 Mar;22(3):164-8.

Culturally appropriate end-of-life care for the Black American.

West SK, Levi L.

Transitions Health System, Inc., 35 Summerhill Drive, Asheville, NC 28804, USA.
transitions@bww.com

PMID: 15017318 [PubMed - in process]

31: Home Healthc Nurse. 2004 Jan;22(1):37-44.

Researching end-of-life care: challenges, strategies, and opportunities.

Head B, Ritchie C.

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PMID: 14734994 [PubMed - indexed for MEDLINE]

32: Home Healthc Nurse. 2004 Jan;22(1):56-9.

What's new in the 2004 Joint Commission home care and hospice standards? Part 1.

Friedman MM.

mmf@mindspring.com

PMID: 14734997 [PubMed - indexed for MEDLINE]

33: Int J Palliat Nurs. 2004 Feb;10(2):84-90.

Evaluation of a night respite community palliative care service.

Kristjanson LJ, Cousins K, White K, Andrews L, Lewin G, Tinnelly C, Asphar D, Greene R.

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A three-phase project was undertaken to develop and evaluate a community night respite palliative care service for patients and family carers. An assessment tool to identify those most in need of night respite was developed and tested. The tool was reliable and feasible for use in practice. Care aides were trained to provide night respite. Fifty-three patients participated over 11 months. Findings revealed the types of patients and families most in need of night respite, the amount of respite needed, and location of death. There is evidence that patients who would have been transferred to an inpatient setting for end-of-life care were able to die at home with the support of the night respite service. Families were extremely appreciative of the service and a limited cost comparison suggested costs were lower than if patients had been transferred to hospital and/or inpatient hospice care. Recommendations for practice are offered.

PMID: 15039612 [PubMed - in process]

34: Int J Palliat Nurs. 2004 Jan;10(1):14.

Patients should choose where they want to die.

Cooley C.

Publication Types:
Editorial

PMID: 14966440 [PubMed - indexed for MEDLINE]

35: Int J Palliat Nurs. 2004 Jan;10(1):6-13.

The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia.

Abbey J, Piller N, De Bellis A, Esterman A, Parker D, Giles L, Lowcay B.

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The need for a specialized clinical regimen for patients with dementia who require palliative care has only recently been recognized. Structured approaches to palliative care are not well developed. The recognition and treatment of pain is an important part of this management risk. However, pain is consistently underdiagnosed and undertreated in this population. A factor contributing to this has been a lack of appropriate tools to help recognize and document pain. This study sought to develop and validate an easy-to-use pain scale for use in residential aged care homes. The tool was developed with residents with end- or late-stage dementia who were unable to articulate their needs, identified by the registered nurses who knew them. Results showed that following pain-relief intervention the average pain score recorded using the scale fell by more than half. A paired Student's t-test showed the reduction to be highly significant ($P < 0.001$). Validity and internal reliability, assessed by calculating Gamma and Cronbach's alpha, were found to be satisfactory. Qualitative evidence gathered

from users of the scale indicated that it was considered a useful clinical device that could be completed within one minute. Further analysis of the use of the scale in clinical settings, testing of inter-rater reliability and examination of the limitations found in this study will commence early in 2004.

Publication Types:
Validation Studies

PMID: 14966439 [PubMed - indexed for MEDLINE]

36: J Am Coll Surg. 2004 Mar;198(3):477-91.

Clinical palliative care for surgeons: part 2.

Lee KF, Johnson DL, Purcell GP, Hinshaw DB, Krouse RS, Baluss M.

Department of Surgery, Baystate Medical Center, Springfield, MA 01199, USA.

PMID: 14992751 [PubMed - indexed for MEDLINE]

37: J Am Geriatr Soc. 2004 Jan;52(1):51-8.

Comment in:
J Am Geriatr Soc. 2004 Jan;52(1):159-60.

Effect of do-not-resuscitate orders on hospitalization of nursing home residents evaluated for lower respiratory infections.

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OBJECTIVES: To determine resident and facility characteristics associated with do-not-resuscitate (DNR) orders and to test the effect of DNR orders on hospitalization of acutely ill nursing home (NH) residents with lower respiratory tract infections (LRIs). **DESIGN:** Prospective cohort. **SETTING:** Thirty-six NHs (almost 4,000 residents) in central and eastern Missouri in the Missouri Lower Respiratory Infection study. **PARTICIPANTS:** NH residents with a LRI (n=1031). **MEASUREMENTS:** Data were obtained from new Minimum Data Set evaluations, resident examination, and chart review. Associations between resident, physician, and facility characteristics and the presence of a DNR order and hospitalization within 30 days from evaluation for an LRI were analyzed. **RESULTS:** Sixty percent of subjects had a DNR order, and 2% had a do-not-hospitalize order. Resident characteristics associated with a DNR order included older age, white race, having a surrogate decision-maker, NH residence for longer than 3 years, and more-impaired cognition. Residents with DNR orders were more likely to live in facilities with more licensed beds, a lower proportion of Medicaid recipients, and a higher prevalence of influenza vaccination. After controlling for potential confounders, residents with a DNR order before the acute illness episode were significantly less likely to be hospitalized (adjusted odds ratio=0.69, 95% confidence interval=0.49-0.97).

CONCLUSION: DNR orders independently reduce the risk of hospitalization for LRI and may function as a marker for undocumented care limitations or as a mandate to limit care (unrelated to resuscitation) in NH residents with LRI.

PMID: 14687315 [PubMed - indexed for MEDLINE]

38: J Am Geriatr Soc. 2004 Jan;52(1):159-60.

Comment on:

J Am Geriatr Soc. 2004 Jan;52(1):51-8.

Do-not-resuscitate orders and hospitalization of nursing home residents: trumping, neglect, or shared decision-making at the eleventh hour.

Teno JM.

Publication Types:

Comment

Editorial

PMID: 14687333 [PubMed - indexed for MEDLINE]

39: J Am Med Dir Assoc. 2004 Mar-Apr;5(2 Suppl):S72-80.

Advance care planning in long-term care facilities.

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Residents of long-term care facilities are at risk of serious medical illnesses and being unable to express choices when difficult treatment decisions must be made. Advance care planning (ACP) allows residents to consider, make, and communicate their preferences for how medical decisions should be made if they are unable to participate in the decision-making process. This article reviews the three steps in ACP: consideration of options and expression of values, communication of decisions, and documentation of the choices. The article defines and describes the particular value of ACP in long-term care facilities, reviews the literature on successful ACP programs in long-term care, and concludes with practical suggestions on how to develop and implement ACP programs.

Publication Types:

Review

Review, Tutorial

PMID: 14984615 [PubMed - indexed for MEDLINE]

40: J Cardiovasc Nurs. 2004 Jan-Feb;19(1):76-83; quiz 84-5.

Hospice as an alternative model of care for older patients with end-stage heart failure.

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The end of life for patients with end-stage heart failure is often characterized by pain, shortness of breath, and diminished quality of life, indicating a lack of adequate care necessary for patients to experience a good death. The vast majority of those who die from heart failure are 65 or older and potentially eligible for the Medicare Hospice Benefit. Yet, only about 10% of patients with end-stage heart failure actually enroll in hospice programs. Lack of enrollment into hospice has been attributed to a variety of factors including a lack of understanding of the availability of hospice as an option for those with heart failure. While improving models of care for patients with heart failure has been of great interest during the last two decades, little is known about the benefits of hospice as a model for care in patients with end-stage heart failure. Nursing must participate in research that explores options of either improving current models of care or developing new and improved models of care for patients with heart failure.

Publication Types:

Review

Review, Tutorial

PMID: 14994785 [PubMed - indexed for MEDLINE]

41: J Clin Nurs. 2004 Feb;13(2):143-9.

Communication with dying patients--perception of intensive care units nurses in Brazil.

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AIMS AND OBJECTIVES: This study aimed to assess whether nurses working in intensive care units view the establishment of communication with patients beyond therapeutic possibilities as an effective palliative therapeutic resource, and which aspects of this communication they valued most. **METHOD:** Data were collected in November 2002, by semi-structured interviews with 10 nurses of both clinical and surgical intensive care unit at a school hospital in Sao Paulo city, Brazil. Interviews were recorded and transcribed to be further analysed according to the qualitative methodology of content analysis. **RESULTS:** Four categories of thematic order raised from the collected statements, which clarify (i) the value of communication with terminal patients; (ii) the obstacles found during this process; (iii) the need to identify the individual demands of each patient, (iv) be able to use communication as a tool in the palliative care of the dying patient. **CONCLUSION:** In conclusion, we found that the nurses working at the intensive care unit do consider communication with dying patients an

effective therapeutic resource, in spite of their own difficulties in communicating with dying patients, viewing themselves as ill prepared to the task, and often, distancing themselves from the dying patients because of their inability to deal with their own feelings, which were brought forth by the confrontation with the imminence of death. RELEVANCE TO CLINICAL PRACTICE: Although the number of interviewed nurses in our study was small, the results corroborated the findings of other studies and revealed an educational aspect in nursing training that deserves serious consideration.

PMID: 14723665 [PubMed - indexed for MEDLINE]

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

Comment on:

J Crit Care. 2003 Sep;18(3):133-41.

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

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Publication Types:

Comment

PMID: 14626210 [PubMed - indexed for MEDLINE]

43: J Crit Care. 2003 Sep;18(3):133-41.

Comment in:

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

Influence of perceived functional and employment status on cardiopulmonary resuscitation directives.

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BACKGROUND: Perceptions about functional and employment status before admission to the intensive care unit (ICU) may influence how patients and clinicians make decisions about cardiopulmonary resuscitation. OBJECTIVE: To examine the relationship between cardiopulmonary resuscitation directives established within 24 hours of admission to the ICU and clinical perceptions of pre-morbid functional and employment status. DESIGN: Prospective observational study in 15 university-affiliated centers in Canada, the United States, Australia, and Sweden. Patients: A total of 1,008 ICU patients aged 18 years or older expected

to stay in the ICU at least 72 hours. Measurements: By using multinomial logistic regression, we examined the relationship between functional status and employment status perceived by the ICU team 1 month before ICU admission (the independent variables) and resuscitation status (the dependent variable). Each patient had either an explicit resuscitation directive (to resuscitate or not to resuscitate), or an implicit resuscitation directive to resuscitate. RESULTS: On average, patients were 61.7 years (+/-17.4 y) old with an Acute Physiology and Chronic Health Evaluation (APACHE) II score of 21.5 (+/-8.7); 846 (83.9%) were ventilated mechanically within 48 hours and 345 (34.2%) died in the ICU. Most patients (793, 78.7%) had no explicit resuscitation directive; 98 (9.7%) had an explicit plan to resuscitate, whereas 117 (11.6%) had an explicit plan of do-not-resuscitate. Of 1,008 patients, 98 (9.7%) were severely functionally limited, 217 (21.5%) were somewhat limited, 628 (62.3%) were totally independent, and 65 (6.4%) had unknown functional status 1 month before ICU admission. Severe functional status impairment was associated moderately with an explicit plan to resuscitate (odds ratio, 2.2 relative to no explicit directive) and associated strongly with an explicit do-not-resuscitate plan (odds ratio, 6.2 relative to no explicit directive, P value on the difference = .011). This relationship was not influenced by age, sex, APACHE II score, medical or surgical status, admission diagnosis, employment status, or city. However, severe functional status was associated strongly and significantly with an explicit do-not-resuscitate directive among those who could not participate in decision making (odds ratio, 8.2; 95% confidence interval, 4.5-15.0), and more weakly associated in those who could participate (odds ratio, 1.7; 95% confidence interval, 0.3-8.6). Being unemployed was associated with an increased odds of an explicit resuscitation directive versus no explicit directive (odds ratio, 5.5; 95% confidence interval, 2.2-13.4). CONCLUSIONS: Functional status impairment perceived by the ICU team is associated clearly with do-not-resuscitate directives in patients unable to participate in decision making. However, the association appears much weaker in patients able to participate in decision making. Patients' perceived employment status also may influence resuscitation decisions. Our results emphasize the challenges of ensuring that crucial resuscitation decisions are not affected adversely by patients' inability to participate in decisions, and by their functional and employment status.

Publication Types:

Multicenter Study

PMID: 14595566 [PubMed - indexed for MEDLINE]

44: J Cult Divers. 2003 Winter; 10(4): 118-23.

Community perspectives on advance care planning: report from the Community Ethics Program.

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The objectives of the Community Ethics Program are to increase community awareness about advance care planning to address patient preferences concerning future care, and to improve hospital-community collaboration around care at end of life in diverse communities. As part of this educational program, community

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forums and focus groups were held with African-American, Korean-American, and Latino communities in Philadelphia between 2000 and 2001. In this paper, we discuss concerns related to end of life and advance care planning specific to each community, as well as themes that cut across communities. Increasing our understanding of community views and perspectives on potential barriers to advance care planning, particularly through a hospital-community partnership, is an important step toward enhancing the quality of end of life care for all patients.

Publication Types:

Review

Review, Tutorial

PMID: 15000054 [PubMed - indexed for MEDLINE]

45: J Gerontol Nurs. 2004 Mar;30(3):26-33.

The nature of long-term care nursing work.

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Data from a pilot study on the nature of nursing work in long-term care (LTC) facilities are compared with data on nursing work in intensive care units (ICUs). The comparison suggests that the LTC nursing work environment is a complex, demanding, and interesting one that is different from, not less than, nursing work in acute care environments. The data also suggests that nursing educators and researchers should reconsider LTC nursing work environments. Long-term care nursing offers an ideal, relatively controlled environment for research on what nursing work is and how nursing interventions affect patient outcomes. Long-term care nurses, whose daily work has always involved working with a variety of professional and unlicensed staff members, can serve as models for delegation and interpersonal skills. Finally, the LTC setting offers the ideal environment for clinical sites in connection with the proposed curriculum changes in end-of-life care for patients and their families.

PMID: 15061451 [PubMed - in process]

46: J Law Med. 2004 Feb;11(3):312-23.

The Dutch Euthanasia Act and related issues.

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In 2002 the Dutch Euthanasia Act came into force. This Act is the result of a lengthy developmental process. It codifies the requirements that have evolved in case law and medical ethics since 1973. Empirical data indicate that the Dutch euthanasia practice is stabilising. Euthanasia and assisted suicide occur in 2.7% of all deaths. Now that the Act has been passed, the focus is on improving

the quality of medical decision-making. From an international perspective, the Dutch legislation is exceptional. However, it appears that other countries and international organisations are considering euthanasia legislation as well. It remains to be seen how influential the Dutch model will prove to be.

Publication Types:
Historical Article
Legal Cases
Review
Review, Tutorial

PMID: 15018208 [PubMed - indexed for MEDLINE]

47: J Law Med. 2004 Feb;11(3):292-311.

Gardner; Re BWV: resolved and unresolved issues at end of life.

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The Medical Treatment Act 1988 (Vic) gives statutory recognition to a patient's (or their agent or guardian if incompetent) right to refuse medical treatment. The case of Gardner; Re BWV confirmed that medical treatment as defined under the Act included artificial nutrition and hydration and as such could be withdrawn, notwithstanding that this would result in the patient's death. This article analyses Gardner; Re BWV and argues that, by deliberately dealing narrowly with the issues at hand, both the Victorian Civil and Administrative Tribunal at first instance and the Victorian Supreme Court knowingly left BWV to die from dehydration over a period of weeks. By not addressing these issues, the tribunal, and more particularly the Supreme Court, lost an opportunity for a reform of the law, so urgently needed at end of life, which would have allowed for "mercy killing", thus sparing BWV and her family the lingering death she was given.

Publication Types:
Legal Cases
Review
Review, Tutorial

PMID: 15018207 [PubMed - indexed for MEDLINE]

48: J Law Med. 2004 Feb;11(3):282-91.

The medical provision of hydration and nutrition: two very different outcomes in Victoria and Florida.

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Decisions to withhold or withdraw medical hydration and nutrition are amongst

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the most difficult that confront patients and their families, medical and other health professionals all over the world. This article discusses two cases relating to lawful withdrawal and withholding of a percutaneous endoscopic gastrostomy tube (PEG) from incompetent patients with no hope of recovery. Victoria and Florida have statutory frameworks that provide for advance directives, however in both *Gardner; Re BWV and Schindler v Schiavo*; *Re Schiavo* the respective patients did not leave documented instructions. The article analyses the two cases and their outcomes from legal, medical and ethical perspectives.

Publication Types:

Legal Cases
Review
Review, Tutorial

PMID: 15018206 [PubMed - indexed for MEDLINE]

49: J Law Med. 2004 Feb; 11(3):265-8.

Withdrawal of artificial life support.

Freckelton I.

Publication Types:

Editorial
Legal Cases

PMID: 15018202 [PubMed - indexed for MEDLINE]

50: J Med Libr Assoc. 2004 Jan; 92(1):78-82.

Information needs at the end of life: a content analysis of one person's story.

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During the last phase of life, a person may need a variety of information to help her or him cope with dying and death. This article describes the nature of information needed during this stage. A content analysis was done of a book of conversations between a husband who was dying and his wife who is a grief counselor to determine his information needs. Four categories of needs were proposed, including physical, emotional, spiritual, and financial. Information needs germane to each category were identified. More research needs to be done by library and information science professionals to determine the information needs of people who are dying, as well as those of their families and the health professionals who care for them.

PMID: 14762466 [PubMed - indexed for MEDLINE]

51: J Nurses Staff Dev. 2004 Mar;20(2):67-68.

Ethical and Legal Issues in End-of-Life Care: Content of the End-of-Life Nursing Education Consortium Curriculum and Teaching Strategies.

&NA; .

PMID: 15071337 [PubMed - as supplied by publisher]

52: J Nurses Staff Dev. 2004 Mar;20(2):59-66.

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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Associate Professor, University of Colorado Health Sciences Center, Denver, Colorado, and ELNEC Advisory Board Member.; Anne Rhome, MPH, RN, is Deputy Executive Director, American Association of Colleges of Nursing, Washington, DC, and ELNEC Co-Investigator.; Marcia Grant, PhD, RN, FAAN, is Research Scientist, City of Hope Medical Center, Duarte, California, and ELNEC Co-Investigator.

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.

PMID: 15071336 [PubMed - as supplied by publisher]

53: J Pain Palliat Care Pharmacother. 2003;17(3-4):231-8.

The international observatory on end of life care: a new initiative to support palliative care development around the world.

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The development of palliative care is proceeding rapidly in some areas of the world, but major problems continue to exist in several countries and regions.

Comparative research evidence to inform palliative care development is limited and can be difficult to obtain, especially for resource poor settings. International collaboration is needed to promote and disseminate an evidence base to support the growth of palliative care. The aims and plans of the newly created International Observatory on End of Life Care are described, together with its orientation to global partnership and collaboration. The Observatory will build on public health models to provide research-based intelligence about palliative care around the world, drawing also on cultural, historical and ethical perspectives.

PMID: 15022966 [PubMed - in process]

54: J Pain Palliat Care Pharmacother. 2003; 17(3-4): 107-18; discussion 119-20.

Pain relief in the developing world: the experience of hospice Africa-Uganda.

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The need for high quality end-of-life care in the developing world is increasingly becoming recognized. One of the core parts of such a service is adequate pain control. Poor health care infrastructures and lack of access to opioid analgesics are common problems. This makes establishing appropriate, sustainable end-of-life care particularly challenging in resource poor settings. Hospice Africa-Uganda has ten years of experience in developing such a service. This paper discusses some of the challenges encountered and how these have been addressed. These include access to opioids, educating of health care workers and influencing policy makers. Factors that have been important in making the service a success, such as choosing an appropriate model of care, and future directions for the organization are discussed.

PMID: 15022955 [PubMed - in process]

55: J Pain Palliat Care Pharmacother. 2003; 17(3-4): 13-22.

Symptom control and palliative care in Chile.

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As in other developed and developing countries, the most common chronic disorders affecting the Chilean population are cardiovascular disease, cancer, cirrhosis, diabetes, chronic obstructive pulmonary disease and external injuries. Availability of oncology services is not extensive and there are no academic programs to adequately train practitioners in either palliative medicine or comprehensive palliative care for allied health professionals including nurses, psychologists and chaplains. Major efforts have been made to incorporate palliative care as an important health care focus in the last decade

and in the development of effective policies for opioid availability. Chile now meets 84% of the 17 criteria outlined by the World Health Organization and the International Narcotics Control Board for opioid availability. Postgraduate medical education in symptom control, clinical use of opioids and end-of-life care remains relatively poor as judged by the results of a questionnaire administered to 158 resident physicians at the Pontificia Universidad Catolica de Chile. Improvements in symptom control and the development of palliative care in Chile will depend on the effective assessment of symptom control effectiveness and improved education and training of health professionals in clinical pharmacology, symptom control, clinical ethics, and end-of-life care.

PMID: 15022948 [PubMed - in process]

56: J Pain Palliat Care Pharmacother. 2003;17(3-4):1-9; discussion 11-2.

Freedom from pain--a mirage or a possibility? experience in attempts to change laws and practices in India.

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The incidence of cancer increases exponentially with age and a large number of cancer patients are the older members of society. In many developing and some developed countries, the disease is usually detected at a stage when it is too late for aggressive anticancer therapy to have the desired effect. Most cancer patients suffer moderate to severe pain during the terminal phase of the disease. This pain is unpredictable and produces fear and anxiety in patients and family members. Morphine is the gold standard analgesic to control this pain, but its availability is restricted. The fear of diversion of morphine for non-medical uses has led to severe control on its availability. Studies have shown that diversion of medical morphine is not really an issue. This paper describes attempts to increase morphine availability through the courts in India. The courts have issued directives to improve the availability of the drug, yet 97% of Indian patients have very poor access to the drug. There is a need to improve access to pain-free end-of-life care. In the absence of morphine, physicians lack experience in its use. They need to be educated to provide for their patients a pain-free life. Patients and their families need to be educated that cancer need not end in a painful death. It is not adequate to be able to manage cancer alone; one needs to free the society from fear of cancer.

PMID: 15022947 [PubMed - in process]

57: J Pain Palliat Care Pharmacother. 2003;17(3-4):153-66; discussion 167-9.

Spiritual care in a multi-religious context.

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Spiritual care is an essential component of palliative care because spirituality is an important part of suffering and the relief of pain and suffering. It is especially important in the developing world where medical and comfort resources are limited. Spiritual resources in the context of many religions are described. Understanding pain from a spiritual perspective and approaches when spiritual resources appear ineffective are discussed. The role of spiritual resources in end-of-life care are described in the context of taking a spiritual inventory. The importance of all palliative care clinicians understanding these concepts is emphasized.

PMID: 15022959 [PubMed - in process]

58: J Palliat Care. 2003 Fall;19(3):176-84.

Women's decision-making needs regarding place of care at end of life.

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Little is known about the decision-making needs of terminally ill women who are considering options for place of care at the end of life. A pilot study was conducted with a sample of 20 terminally ill women with advanced cancer to identify factors taken into consideration in making this decision. Participants were interviewed using a semistructured questionnaire incorporating the domains of quality of end-of-life care and based on the Ottawa Decision Support Framework. Results suggested a gap between the preferred (home, n = 13) and the actual (palliative care unit, n = 16) place of care. Discrepancies about place of care may be related to conflicting subjective factors such as being a burden to family versus having the opportunity to strengthen relationships with family and friends. Participants who were actively engaged in making the decision scored the highest levels of decisional conflict. Previous studies have shown an association between high decisional conflict scores and decision delay. Although findings from this small study are preliminary, they suggest that the decision regarding place of terminal care is complex with multiple competing factors being considered.

PMID: 14606329 [PubMed - indexed for MEDLINE]

59: J Palliat Care. 2003 Fall;19(3):188-91.

A comparison of attitudes of medical students in England and in South Africa towards patients with life-limiting illness.

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All medical schools in the U.K. now include teaching in palliative care in the undergraduate curriculum, and this is mirrored in Europe and the U.S.A. In South

Africa, however, palliative care education and provision are not widely available. An increasing number of medical and nursing staff are invited to teach palliative care in other countries. Such teaching should, however, take into account the cultural attitudes the students have towards the care of patients with a chronic or terminal illness. Nineteen statements on attitudes were constructed, and medical students in Leicester, U.K., and in Medunsa, South Africa, were invited to respond to them using a 10-point Likert scale. The questionnaire was distributed before either cohort of students had received any teaching in this area. Students in South Africa were significantly more likely to want to work in a speciality where most patients were likely to be cured ($p < 0.001$) and significantly less likely to believe that caring for dying patients could be rewarding ($p < 0.001$). South African medical students had significantly fewer positive attitudes than had their U.K. counterparts toward patients being informed of a terminal prognosis ($p < 0.001$). This study indicates that cultural differences between medical students may have an effect on the teaching of care for patients with life-limiting illness. This has relevance for curriculum delivery, especially when professionals are invited to teach or develop material on palliative care for other countries.

PMID: 14606331 [PubMed - indexed for MEDLINE]

60: J Palliat Care. 2003 Fall;19(3):217-9.

The challenge of communicating intent of sedation in advanced illness.

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Publication Types:
Case Reports

PMID: 14606337 [PubMed - indexed for MEDLINE]

61: J Palliat Care. 2003 Fall;19(3):168-75.

What is a good death? Minority and non-minority perspectives.

Tong E, McGraw SA, Dobihal E, Baggish R, Cherlin E, Bradley EH.

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While much attention has been directed at improving the quality of care at the end of life, few studies have examined what determines a good death in different individuals. We sought to identify common domains that characterize a good death in a diverse range of community-dwelling individuals, and to describe differences that might exist between minority and non-minority community-dwelling individuals' views. Using data from 13 focus groups, we identified 10 domains that characterize the quality of the death experience: 1) physical comfort, 2) burdens on family, 3) location and environment, 4) presence

of others, 5) concerns regarding prolongation of life, 6) communication, 7) completion and emotional health, 8) spiritual care, 9) cultural concerns, 10) individualization. Differences in minority compared to non-minority views were apparent within the domains of spiritual concerns, cultural concerns, and individualization. The findings may help in efforts to encourage more culturally sensitive and humane end-of-life care for both minority and non-minority individuals.

PMID: 14606328 [PubMed - indexed for MEDLINE]

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

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

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PMID: 14622468 [PubMed - indexed for MEDLINE]

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

Ambulatory hospice training in family medicine residency.

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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 - indexed for MEDLINE]

64: J Palliat Med. 2003 Oct;6(5):775-6.

Information for patients and families about ventilator withdrawal.

von Gunten C, Weissman DE.

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PMID: 14622460 [PubMed - indexed for MEDLINE]

65: J Palliat Med. 2003 Oct;6(5):771.

Comment on:

J Palliat Med. 2003 Feb;6(1):69-75.

Hospice and nonhospice nursing home residents.

Miller SC, Mor V.

Publication Types:

Comment

Letter

PMID: 14622457 [PubMed - indexed for MEDLINE]

66: J Palliat Med. 2003 Oct;6(5):774-5.

Symptom control for ventilator withdrawal in the dying patient.

Von Gunten C, Weissman DE.

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92103-1407, USA. cvongunt@sdhospice.com

PMID: 14622459 [PubMed - indexed for MEDLINE]

67: J Palliat Med. 2003 Oct;6(5):773-4.

Ventilator withdrawal protocol.

von Gunten C, Weissman DE.

Center for Palliative Studies, San Diego Hospice, San Diego, California
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PMID: 14622458 [PubMed - indexed for MEDLINE]

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

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

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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 - indexed for MEDLINE]

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

Palliative care management: a Veterans Administration demonstration project.

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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

Library Program Office
Office of Information
Veterans Health Administration

institution-wide.

PMID: 14622470 [PubMed - indexed for MEDLINE]

70: 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.

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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 - indexed for MEDLINE]

71: J Palliat Med. 2003 Oct;6(5):769-70.

The evolution of the advanced practice nurse within palliative care.

Coyne PJ.

Publication Types:
Editorial

PMID: 14622456 [PubMed - indexed for MEDLINE]

72: 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.

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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 - indexed for MEDLINE]

73: 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.

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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.

Publication Types:
Evaluation Studies

PMID: 14622451 [PubMed - indexed for MEDLINE]

74: 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.

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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 - indexed for MEDLINE]

75: JAMA. 2004 Mar 24;291(12):1445-6; author reply 1446.

Comment on:

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

Memories of loved ones about care at the end of life.

Weiss CO, Finucane TE.

Publication Types:

Comment

Letter

PMID: 15039410 [PubMed - indexed for MEDLINE]

76: Lancet Neurol. 2004 Mar;3(3):144.

End-of-life care and bereavement: effect on family carers.

Volicer L.

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Publication Types:

Review

Review, Tutorial

PMID: 14980528 [PubMed - indexed for MEDLINE]

77: Med Decis Making. 2003 Nov-Dec;23(6):502-10.

Attitudes, sociodemographic characteristics, and actual end-of-life decisions of physicians in Flanders, Belgium.

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AIM: To study the effect of sociodemographic and attitudinal determinants of physicians making end-of-life decisions (ELDs). METHODS: The physicians having signed 489 consecutive death certificates in the city of Hasselt (Belgium) were sent an anonymous questionnaire regarding their ELDs and another on their attitudes toward voluntary euthanasia (EUTH) and physician-assisted suicide (PAS). RESULTS: 55% response rate. Nontreatment decisions occurred in 16.7% of

all death cases; in 16%, there was potentially life-shortening use of drugs to alleviate pain and symptoms; in 4.8% of cases, death was deliberately induced by lethal drugs, including EUTH, PAS, and life termination without explicit request by the patient. In their attitudes toward EUTH and PAS, the 92 responding physicians clustered into 3 groups: positive and rule oriented, positive rule-adverse, and opposed. Cluster group membership, commitment to life stance, years of professional experience, and gender were each associated with specific ELD-making patterns.

PMID: 14672110 [PubMed - indexed for MEDLINE]

78: Med Econ. 2004 Jan 9;81(1):83-4.

"Doc, we need to pray."

Dalton SD.

PMID: 14959608 [PubMed - indexed for MEDLINE]

79: Nephrol Nurs J. 2003 Dec;30(6):649-56, 664.

Resources for planning palliative and end-of-life care for patients with kidney disease.

Price CA.

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Historically, Americans have died of infectious diseases, often in childhood or young adulthood. Cancer has also been responsible for thousands of deaths. With the advent of improved antibiotics and chemotherapy, people are surviving much longer and many, especially those over 65 years of age, will incur at least one chronic disease or disability in their lifetime. As the health care emphasis has changed from intervening for acute illness to treating the adverse effects of chronic disease, our health care system has also somewhat shifted gears. Unlike serious acute illness, chronic illness generally does not lead to a swift death in a hospital, but rather to a prolonged course of symptom management in the home setting or a long-term care facility. In some situations, the patient or family are battling a disease process where death is inevitable. Although holding on for a cure, the patient and family may begin considering the option of a dignified and peaceful death. In the care of renal patients, nephrology nurses have an expanded and important role in assisting patients with their decisions concerning palliative and end of life care and in providing that care. Fortunately, resources are now available to assist with the coordination of a therapeutic plan of care.

Publication Types:

Review

Review, Tutorial

PMID: 14730785 [PubMed - indexed for MEDLINE]

80: Nord J Psychiatry. 2003;57(6):469-71.

Gender biases in decisions on euthanasia among Swedish jurors.

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The present study set out to investigate whether group-based biases may influence decisions regarding euthanasia in Swedish jurors (namndeman). Thirty-eight Swedish jurors were presented with a case description of euthanasia in a severely brain-damaged patient. Age and gender of the patient were systematically varied. The jurors were asked to what extent they believed that euthanasia was ethical in the case presented to them and whether they thought that it should be legal. Jurors tended to be supportive of euthanasia and were more so when it was used on patients who belonged to the opposite gender. These results suggest that group-based biases may influence decisions regarding euthanasia in Swedish jurors. The finding has implication for the Swedish debate regarding a possible legalization of such procedures.

PMID: 14630553 [PubMed - indexed for MEDLINE]

81: Nurs Educ Perspect. 2004 Jan-Feb;25(1):26-9.

TNEEL workshop. Interactive methods for teaching end-of-life care.

Wilkie DJ, Lin YC, Judge MK, Shannon SE, Corless IB, Farber SJ, Brown MA.

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Nurse educators have identified lack of end-of-life content as a serious deficit in undergraduate nursing education. TNEEL, a new software program with tools for teaching end-of-life topics, was created to help educators overcome this problem. The authors implemented an experiential workshop to help educators learn how to use TNEEL's wide variety of educational tools. Trainers provided information about TNEEL and coached participants (N = 94) as they practiced using laptop computers to increase their familiarity and comfort in using the toolkit. Workshop participants completed pre- and posttest evaluations addressing their opinions and beliefs about using this computer tool. Findings support the workshop as an effective way to facilitate adoption of this innovative educational resource and support the development of a nation-wide training plan for TNEEL with experiential workshops.

PMID: 15017797 [PubMed - indexed for MEDLINE]

82: Nurs Manage. 2004 Mar;35(3):34, 36-40.

Bringing end-of-life care out of the shadows.

Rushton CH, Spencer KL, Johanson W.

Berman Bioethics Institute.

Understand what resources are available to help you incorporate palliative and end-of-life care into your nursing practice.

PMID: 15021800 [PubMed - in process]

83: Oncology (Huntingt). 2004 Mar;18(3):363-8; discussion 373-5.

Surviving the stresses of clinical oncology by improving communication.

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Oncologists grapple with an element of psychological stress that relates to the suffering their patients experience. Although this stress may not be unique to oncology, it is profound. When these stresses become overwhelming, they lead to physician burnout. It is important to understand what makes an oncologist feel successful, what coping strategies help combat burnout, and what adds to the process of renewal. The doctor-patient relationship plays an important role for many oncologists in this regard, and communication skills are increasingly recognized for their importance in this arena. We outline several clinical scenarios that pose particular challenges to oncologists. These include breaking bad news and the patient's response to hearing bad news, transitions in care and offering end-of-life care, participation in investigational studies, error disclosure, complementary and alternative medicine, spirituality, family discussions, and cross-cultural issues. By highlighting the relevant psychosocial issues, we offer insight into, and tools for, an enriched dialogue between patient and oncologist. The doctor-patient relationship can be viewed as the ultimate buffer for dealing with the hassles encountered in clinical oncology.

PMID: 15065704 [PubMed - in process]

84: Palliat Med. 2004 Jan;18(1):53-61.

The needs of terminally ill patients at home: directing one's life, health and things related to beloved others.

Proot IM, Abu-Saad HH, ter Meulen RH, Goldsteen M, Spreeuwenberg C, Widdershoven GA.

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This article describes the results of a grounded theory study among terminally ill patients (with a life expectancy of less than three months) at home (n = 13,

aged 39-83). The most commonly recurring theme identified in the analysis is 'directing', in the sense of directing a play. From the perspectives of patients in our study, 'directing' concerns three domains: 1) directing one's own life; 2) directing one's own health and health care; and 3) directing things related to beloved others (in the meaning of taking care of beloved ones). The patient's directing is affected by impeding and facilitating circumstances: the patient's needs and problems in the physical, psychological and existential/spiritual domain, and the support by family members and providers. Supporting patients and families, stimulating the patients' directing, giving attention to all domains of needs and counselling patients' families in the terminal phase are issues that need attention and warrant further investigation.

PMID: 14982208 [PubMed - indexed for MEDLINE]

85: Palliat Med. 2004 Jan;18(1):77-9.

Prognostic assessment in terminally ill cancer patients: from evidence-based knowledge to a patient-physician relationship and back.

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PMID: 14982216 [PubMed - indexed for MEDLINE]

86: Pharm World Sci. 2003 Dec;25(6):288-93.

"Death was a blessing"--should it ever be pharmaceutically hastened? British pharmacists' views.

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OBJECTIVES: To investigate the views and experiences of British pharmacists in physician-assisted suicide (PAS) and voluntary active euthanasia (VAE) and to examine whether differences in views were associated with personal characteristics. **METHOD:** A postal questionnaire was mailed to a random sample of 500 registered pharmacists, with addresses in England or Wales, stratified according to sex and community/hospital working environments. **MAIN OUTCOME MEASURE:** Pharmacists' reports of their views and experiences of PAS and VAE. **RESULTS:** Completed questionnaires were received from 295 respondents (response rate: 59%). The majority of respondents (83%) reported that at times, a person had the right to choose their own manner of death; 61% and 53% thought that there should be changes in the Law to legalise VAE and PAS, respectively. If it were legal to do so, 63% stated that they would be willing to dispense medication for VAE and 64% for PAS. However, only 45% agreed that the pharmacist should have a role in advising the prescriber on the choice and dose of drugs

used. Sex, age, and years registered as a pharmacist were not found to be significantly associated with views on the practices of PAS and VAE. However, pharmacists who reported having a religion were significantly less likely to favour such practices. On comparing the views of community and hospital pharmacists, community pharmacists were significantly less likely than expected to want to be informed about the intended purpose of lethal drugs. CONCLUSION: In this survey, while over half of British pharmacists did not disagree in principle to the legalisation of VAE and/or PAS, they were less supportive of direct involvement in such procedures. Religion was a discriminatory factor associated with negative views of VAE and PAS. The significant minority of pharmacists not wanting to know the purpose of drugs they suspected might be for PAS or VAE is not in accordance with professional accountability, reflecting the complex and sometimes conflicting legal and moral aspects of such practices when deciding upon a course of action.

PMID: 14689818 [PubMed - indexed for MEDLINE]

87: Provider. 2004 Feb;30(2):35-7.

Navigating the hospice benefit.

Markenson AJ, Adelglass C.

Epstein Becker and Green, New York, USA.

PMID: 14964919 [PubMed - indexed for MEDLINE]

88: Resuscitation. 2003 May;57(2):139-44.

Improving decision-making and documentation relating to do not attempt resuscitation orders.

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INTRODUCTION: Do not attempt resuscitation (DNAR) decision-making and recording

in case notes can be poor. We have audited current practices pertaining to DNAR orders in a district hospital before and after the introduction of a standardised order form (SOF). METHODOLOGY: DNAR decisions in medical case notes

were audited before and after the introduction of a SOF. All aspects of the decision were scrutinised against recommended guidelines (BMA/RCN/RC (UK) London: BMA, 1999). RESULTS: Case notes of 156 patients were examined. A total of 62 (39.7%) had combined case note and SOF documentation (Gp1), while 94 (60.3%) had case note documentation only (Gp2). Some 61/62 (98.4%) of DNAR indications in Gp1 were in accordance with guidelines versus 81/94 (86.2%) in GP2 (P<0.01) and 50/62 (80.6%) of decisions were reviewed in GP1 versus 36/94 (38.3%) in GP2 (P<0.001). More decisions were authorised by consultants in GP1

(56/62 (90.3%) vs. 35/94 (37.2%) $P < 0.001$) and had active patient participation (9/62 (14.5%) vs. 1/94 (1.1%) $P < 0.001$) compared with Gp2. CONCLUSION: Documentation of DNAR decisions in medical case notes is poor. Standardised order forms, based on recommended national guidelines that complement case note entries, improve the process and recording of this sensitive decision.

PMID: 12745181 [PubMed - indexed for MEDLINE]

89: RN. 2004 Jan;67(1):25-8.

End-of-life decisions: the family's role.

Haddad A.

Center for Health Policy and Ethics, Creighton University, Omaha, USA.

PMID: 14979188 [PubMed - indexed for MEDLINE]

90: SCI Nurs. 2003 Winter;20(4):263-5.

Innovative practices improve end-of-life care.

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Publication Types:

Review

Review, Tutorial

PMID: 15005059 [PubMed - indexed for MEDLINE]

91: SCI Nurs. 2003 Winter;20(4):238-49.

Establishing an end-of-life program in an academic acute care hospital.

Counsell C, Adorno G, Guin P.

Shands Hospital, University of Florida, Gainesville, Florida, USA.

The primary goal of end-of-life (EOL) care is to relieve suffering through measures that improve comfort and address the psychological, social, and spiritual needs of the dying. This article discusses the components of a pilot project that focused on palliative EOL care at an academic acute care hospital. An interdisciplinary team of nurses, social workers, chaplains, patient care coordinators, and advanced practice nurses established a common vision for the care of patients who were "in the dying process," or were expected to die during their hospitalizations. A nurse-social worker "Care-Pair Team" completed a consistent interdisciplinary EOL care needs assessment when treatment goals became strictly palliative. Interventions were driven by a clinical pathway and

a pre-printed physician's order set that continually clarified the goals of treatment. Key elements of the program included leadership support, advance directives, education, communication, family involvement, symptom management, professional collaboration, and outcomes measurement.

PMID: 15005055 [PubMed - indexed for MEDLINE]

92: SCI Nurs. 2003 Winter;20(4):230-1.

End of life issues: renewed meaning for care of the dying in America.

Parsons LC.

The subject of death is a topic that many Americans, including their health care providers, have avoided talking about for many decades. End-of-life care is capturing the attention of many in our country and rightfully so. Dying is one aspect of life that we will all face. Dying should be a culmination of one's life and not a dreaded subject, as many dying persons want to talk about their end of life, discuss their final wish, and say farewell to loved ones and family. Health care providers need to become more educated in end-of-life issues and look to becoming certified in palliative care. Comfort and closure are important attributes of providing "quality" palliative care. This issue is dedicated to raising members of the American Association of Spinal Cord Injury Nurses, and the American public's awareness of end-of-life issues. Our feature articles and some of our columns address this topic. Enjoy this issue and share it with your colleagues!

Publication Types:

Editorial

PMID: 15005054 [PubMed - indexed for MEDLINE]

93: Semin Speech Lang. 2003 Nov;24(4):285-99.

Ethical issues in dysphagia: when patients refuse assessment or treatment.

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The primary goal of intervention for patients with dysphagia is to restore oral feeding. When patients are unable to achieve adequate nutrition, hydration, or safety with oral feeding, then nonoral approaches are often recommended. Although patients' rights to accept or refuse clinical recommendations are widely recognized, when a patient refuses tube feeding or other recommendations, dysphagia specialists are left with a host of practical questions about their role in caring for the patient. We review the criteria for assessing patients' capacity to make informed choices, approaches to decision making when patients lack capacity, and the roles and responsibilities of clinicians when patients choose high-risk treatment options.

Publication Types:
Case Reports

PMID: 14722802 [PubMed - indexed for MEDLINE]

94: Soc Sci Med. 2004 Mar;58(5):955-66.

"You're not going to dehydrate mom, are you?": Euthanasia, versterving, and good death in the Netherlands.

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In 1996, a debate erupted in the Netherlands about versterven: dying as a result of abstaining from eating and drinking. This discussion initially appeared to be one of the many side-shows to the wider Dutch euthanasia debate, but it continued to dominate the debate for the next few years, with newspaper headlines reporting "involuntary dehydration" in nursing homes. Part of the reason for this was the term itself. Introduced to refer to terminal dehydration, the word versterven had peculiar connotations and this, together with the way in which it was used, caused much confusion and controversy. Was versterven related to euthanasia? Did it denote dying naturally and peacefully or a horrible death imposed on helpless psychogeriatric patients? Was it (could it be) voluntary? Was the patient in control? Was it good death? This paper examines the discussion about, and the media representations of, versterven, focusing on its ambiguity and its relationship to good death.

PMID: 14732608 [PubMed - indexed for MEDLINE]

95: Soc Sci Med. 2004 Mar;58(5):939-53.

Narrative nuances on good and bad deaths: internists' tales from high-technology work places.

DeVecchio Good MJ, Gadmer NM, Ruopp P, Lakoma M, Sullivan AM, Redinbaugh E, Arnold RM, Block SD.

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Public and professional discourses in American society about what constitutes a "good death" have flourished in recent decades, as illustrated by the pivotal SUPPORT study and the growing palliative care movement. This paper examines a distinctive medical discourse from high-technology academic medical centers through an analysis of how physicians who are specialists in internal medicine tell stories about the deaths of patients in their care. 163 physicians from two major academic medical centers in the United States completed both qualitative open interviews and quantitative attitudinal measures on a recent death and on the most emotionally powerful death they experienced in the course of their

careers. A subsample of 75 physicians is the primary source for the qualitative analysis, utilizing Atlas-ti. "Good death" and "bad death" are common in popular discourse on death and dying. However, these terms are rarely used by physicians in this study when discussing specific patients and individual deaths. Rather, physicians' narratives are nuanced with professional judgments about what constitutes quality end-of-life care. Three major themes emerge from these narratives and frame the positive and negative characteristics of patient death. Time and Process: whether death was expected or unexpected, peaceful, chaotic or prolonged; Medical Care and Treatment Decisions: whether end-of-life care was rational and appropriate, facilitating a "peaceful" or "gentle" death, or futile and overly aggressive, fraught with irrational decisions or adverse events; Communication and Negotiation: whether communication with patients, family and medical teams was effective, leading to satisfying management of end-of-life care, or characterized by misunderstandings and conflict. When these physicians' narratives about patient deaths are compared with the classic sociological observations made by Glaser and Strauss in their study *A Time for Dying* (1968), historical continuities are evident as are striking differences associated with rapid innovation in medical technologies and a new language of medical futility. This project is part of a broader effort in American medicine to understand and improve end-of-life care.

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Good enough death: autonomy and choice in Australian palliative care.

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This paper draws upon Australian fieldwork to trace the changing notions of a good death held by hospice and palliative care practitioners. Palliative care practitioners search for an ideology to inform their practice within the context of a complex society for which there is no one good death. Social demographics, the multicultural nature of society and institutional constraints frame the experience of dying in complex ways, while contemporary social responses to dying reflect the uncertainties held by many Australians. Despite the fragmentation evident within contemporary Australian society, the hospice movement in Australia and in other Western contexts has sought to reintroduce a ritual for dying. The good death ideology of the original hospice movement proposed a manner of dying in which open communication and acceptance of death were actively encouraged. The hospice model of a good death, however, has become increasingly inappropriate in the current climate of patient autonomy and consumer choice. The practice of palliative care, a holistic form of care for dying people, which follows the individualistic ethic of choice, has emerged from and replaced the original hospice movement. Consequently, the good death of the original hospice movement has been abandoned in favour of a philosophy of a 'good enough' death. However, what may appear a compromise informed by ethical practice masks a return to routine medical practices and a hierarchy of care which prioritises the physical management of symptoms. It appears that while palliative care practitioners may often fail in their facilitation of a good death for their patients, they can be proactive in alleviating their patients'

pain and physical discomfort.

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Media constructions of dying alone: a form of 'bad death'.

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In this study, newspaper accounts of people who die alone are analysed, drawing on a sample of 90 articles in the anglophone press that appeared in October 1999. Dying alone is represented as a fearful fate and a moral affair, often being the outcome of an undesirable personal character, either of the deceased or of onlookers, or involving the failings of society at large. It is frequently portrayed as occurring to people who are either geographically or socially distant from 'home', so that an imagined community of readers is encouraged to contemplate a death alone as the consequence of personal or societal breakdown. A degree of stigmatisation, sometimes of those who die alone, sometimes of those perceived to have caused this event, was evident. The negative evaluation of death alone parallels that found in some traditional societies where a death far from home is considered 'bad'. Dying alone contrasts significantly with the sociable, 'good', confessional deaths of newspaper columnists and other media celebrities facing terminal illness.

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Cultural scripts for a good death in Japan and the United States: similarities and differences.

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Japan and the United States are both post-industrial societies, characterised by distinct trajectories of dying. Both contain multiple "cultural scripts" of the good death. Seale (Constructing Death: the Sociology of Dying and Bereavement, Cambridge University Press, Cambridge, 1998) has identified at least four "cultural scripts", or ways to die well, that are found in contemporary anglophone countries: modern medicine, revivalism, an anti-revivalist script and a religious script. Although these scripts can also be found in Japan, different historical experiences and religious traditions provide a context in which their content and interpretation sometimes differ from those of the anglophone countries. To understand ordinary people's ideas about dying well and dying poorly, we must recognise not only that post-industrial society offers multiple scripts and varying interpretive frameworks, but also that people actively select from among them in making decisions and explaining their views. Moreover,

ideas and metaphors may be based on multiple scripts simultaneously or may offer different interpretations for different social contexts. Based on ethnographic fieldwork in both countries, this paper explores the metaphors that ordinary patients and caregivers draw upon as they use, modify, combine or ignore these cultural scripts of dying. Ideas about choice, time, place and personhood, elements of a good death that were derived inductively from interviews, are described. These Japanese and American data suggest somewhat different concerns and assumptions about human life and the relation of the person to the wider social world, but indicate similar concerns about the process of medicalised dying and the creation of meaning for those involved. While cultural differences do exist, they cannot be explained by reference to 'an American' and 'a Japanese' way to die. Rather, the process of creating and maintaining cultural scripts requires the active participation of ordinary people as they in turn respond to the constraints of post-industrial technology, institutions, demographics and notions of self.

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Oral morphine and respiratory function amongst hospice inpatients with advanced cancer.

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BACKGROUND: Respiratory depression is the opioid adverse effect feared most by physicians. This may hinder adequate dosing in cancer pain. The study was conducted to examine the respiratory function of patients with advanced cancer receiving significant doses (>100 mg/24 h) of oral morphine. **PATIENTS AND METHODS:** Consecutive pain-free hospice inpatients with advanced cancer receiving high-dose immediate-release oral morphine were evaluated. A single assessment of respiratory rate (RR), arterial blood gas (ABG), and peak flow rate (PFR) was made at assumed morphine steady state. Venous blood was drawn for a trough morphine plasma level. **RESULTS:** Of 31 patients who consented to examination, 20 completed the study assessment; 12 had chronic bronchitis. The median morphine dose was 30 mg 4-hourly (range 20 to 90 mg). Only one patient had evidence of ventilatory impairment. **CONCLUSIONS:** Morphine does not commonly cause chronic ventilatory impairment when given in this way in this population even in the presence of pre-existing or concurrent respiratory disease. Oral morphine given repeatedly in individualized dosage is a safe and efficacious analgesic in the majority of those with advanced cancer.

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100: Support Care Cancer. 2003 Nov;11(11):696-9. Epub 2003 Jul 25.

Caring for dying patients--what are the attitudes of medical students?

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Students entering medical school today will encounter an ageing population and a higher incidence of patients with terminal and life threatening illness. This study was carried out to determine the attitudes of pre-clinical medical students towards the care of patients for whom a cure is not possible. All students were invited to complete a 23-item questionnaire prior to any teaching in palliative care. Of the 186 students who participated in the study, 151 (79%) completed the pre-teaching questionnaire (males=59; females 90; median age 20 years; range 19-27]. Attitudes towards chronically ill and dying patients were generally positive. When comparing age with attitudes it was found that increasing age was associated with a more positive view of caring for patients with chronic or terminal illness, a more positive view of listening to patients reminisce and a more positive view of patients dying at home. Caring for patients at the end of life can be one of the most rewarding aspects of being a doctor. This study suggests that the majority of medical students have a positive attitude towards patients with chronic and terminal illness-the trend for encouraging older students to enter medicine may be an influencing factor.

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Palliative care: end of life care.

Spence D.

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End of life care. Perspectives from families and caregivers.

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In industrialized countries, there is growing attention to improving the quality of healthcare provided to patients with terminal or chronic illnesses as they near the end of their lives. Many patients in wealthy nations reportedly die in severe pain, but little has been documented about pain or suffering at the end of life in less economically developed nations. This qualitative study explores end of life concerns in the Caribbean among health professionals and people who had lost a loved one. It found that many patients with terminal illnesses chose to die in their homes where they could be cared for by family and/or friends,

but that these patients endured much pain and their caregivers also suffered. In the absence of national or institutional policy on pain relief or end of life care, most of these patients and their caregivers seek spiritual comfort. This paper illustrates the need for health professionals and policy makers to do more to relieve suffering at the end of life.

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Quality of life in hospice patients with terminal illness.

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To better understand quality of life (QOL) and its important correlates among patients with terminal illness, a cross-sectional correlational design was used in a study based on Stewart, Teno, Patrick, and Lynn's conceptual model of factors affecting QOL of dying patients and their families. Sixty participants were recruited from two local hospice programs in the midwestern region of the United States. Data were collected at the participants' homes. The participants had an above average QOL. Living with the caregiver, spirituality, pain intensity, physical performance status, and social support as a set explained 38% of the variance in their QOL. Among these five predictors, living with the caregiver, spirituality, and social support statistically were significant predictors of the QOL of these participants. Participants who did not live with their caregivers experienced less pain intensity, perceived higher spirituality, had more social support, and had a significantly better QOL. Important contributions of these findings are discussed.

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