



END OF LIFE CARE BIBLIOGRAPHY March 2004

1: Aging Ment Health. 2003 Sep;7(5):376-82.

Caregiving and its impact on families of the terminally ill.

Brazil K, Bedard M, Willison K, Hode M.

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Changes in the health care system have meant that increasing numbers of the terminally ill receive the majority of their care at home. The purpose of this paper was to document patterns of informal and formal care provided to the terminally ill and assess the impact caregiving has on family members. One hundred and fifty-one family caregivers were recruited for interviews from two community-nursing agencies in an urban region of the province of Ontario, Canada. The majority of respondents 119 (79%) were the female spouses of the patient. The numbers of caregivers providing assistance in specific functional activities were: bathing, 133 (88%); mobility, 123 (81%); dressing and undressing, 114 (76%); toileting, 101(67%), and assistance at night 97 (64%). Sixty-two (41%) respondents reported that they had been providing some form of caregiving for over one year. They also reported that physical demands in caregiving increased substantially during the last three months of the care recipient's life. As family caregivers provided more assistance in activities of daily living they were at greater risk of reporting high caregiver burden. The results of this paper identify the types of care provided by family caregivers of the terminally ill and the impact these demands have on the family caregiver.

PMID: 12959807 [PubMed - indexed for MEDLINE]

2: Alzheimer Dis Assoc Disord. 2003 Oct-Dec;17(4):215-22.

Comment in:

Alzheimer Dis Assoc Disord. 2003 Oct-Dec;17(4):199-200.

Advance directives for health care and research: prevalence and correlates.

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Patients suffering from Alzheimer disease and other types of dementia gradually lose their decision-making capacity. Advance directives have been widely promoted as a means to maintain some control over one's life in the event of decisional incompetence. This study used data from a recent postal survey conducted in Quebec, Canada to: 1) estimate the prevalence of formal and informal advance directives for health care and research among community-dwelling older adults presumed free of cognitive deficits; and 2) characterize those who have communicated their preferences regarding health care and research participation.

Prevalence rates vary from 7.4% (formal advance directives for research) to 42.3% (informal advance directives for health care).

Following multivariate logistic regressions, individuals who have communicated their wishes regarding future health care were found to be older, predominantly women, and to more often know someone with cognitive impairment. Those who have expressed their wishes regarding future research involvement were more inclined to participate in research. They were also more likely to have discussed or written advance directives for health care. The finding that only a small proportion of older adults have discussed future research participation with their families points to the need to find effective ways to promote advance directives for research in this population.

PMID: 14657785 [PubMed - indexed for MEDLINE]

3: Am J Med Sci. 2004 Jan;327(1):25-32.

Advance care planning: does patient gender make a difference?

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BACKGROUND: Although it has received little study, gender may significantly affect patients' attitudes about advance care planning. METHODS: We asked 26 Mexican American (14 male, 12 female), 18 European American (7 male, 11 female), and 14 African American (7 male, 7 female) inpatients for their attitudes about advance care planning and dying. Coders of different ethnicities and genders performed independent, blinded content analyses of responses. RESULTS: The interviews identified 40 themes. Five, including "Advance directives (ADs) improve the chances a patient's wishes will be followed," characterized both genders of all 3 ethnic groups. Although no individual themes distinguished the genders across ethnic groups, 3 meta-themes--or clusters of related themes--did. Men's end-of-life wishes addressed functional outcome alone, but women's wishes addressed other factors, too. Men felt disempowered by the health system, but women felt empowered. Men feared harm from the system, but women anticipated benefit. Each ethnic group expressed these gender differences uniquely. For example, most Mexican American men preferred death to disability, believed "the health care system controls treatment," and wanted no "futile" life support. In contrast, most Mexican American women expressed wishes only about care other than life support (especially about when and where they wanted to die), believed ADs "help staff know...(such) wishes," and trusted the system to "honor (written) ADs." CONCLUSION: Core cultural attitudes observed in both genders of 3 ethnic groups may extend to all Americans. Although core attitudes may support advance care planning for many Americans, health professionals should consider tailoring it to other, ethnic- and gender-specific attitudes.

PMID: 14722393 [PubMed - indexed for MEDLINE]

4: Ann Intern Med. 2004 Mar 2;140(5):402-3; author reply 404.

Comment on:

Ann Intern Med. 2003 May 6;138(9):743-6.

Advance directives, due process, and medical futility.

Berger JT.

Publication Types:

Comment

Letter

PMID: 14996685 [PubMed - indexed for MEDLINE]

5: Ann Intern Med. 2004 Mar 2;140(5):403-4; author reply 404.

Comment on:

Ann Intern Med. 2003 May 6;138(9):743-6.

Advance directives, due process, and medical futility.

Flamm AL, Smith ML.

Publication Types:

Comment

Letter

PMID: 14996687 [PubMed - indexed for MEDLINE]

6: Ann Intern Med. 2004 Mar 2;140(5):403; author reply 404.

Comment on:

Ann Intern Med. 2003 May 6;138(9):743-6.

Advance directives, due process, and medical futility.

Finucane TE.

Publication Types:

Comment

Letter

PMID: 14996688 [PubMed - indexed for MEDLINE]

7: Ann Intern Med. 2004 Feb 17;140(4):269-77.

Medicare program expenditures associated with hospice use.

Campbell DE, Lynn J, Louis TA, Shugarman LR.

Medical Outcomes Research and Evaluation Services, Thetford, Vermont, USA.

BACKGROUND: Hospice providers contend that enrollment reduces the cost of the Medicare programs, but estimates of effects are dated, methodologically limited, and focused on persons with cancer. **OBJECTIVE:** To estimate the effects of hospice care on Medicare program payments during the last year of life from 1996 to 1999 within cohorts defined by age and diagnosis. **DESIGN:** Retrospective cohort. **SETTING:** Deceased Medicare enrollees. **PARTICIPANTS:** Elderly Medicare fee-for-service beneficiaries who received 36 months of continuous Part A and B coverage before death during 1996 to 1999 (n = 245 326). Age- and condition-specific (cancer or noncancer and principal condition) cohorts were defined. **MEASUREMENTS:** Medicare expenditures in the last year of life, as a total figure and by service type. The cost effects of hospice were estimated by using linear regression within the cohorts for hospice enrollees compared with nonenrollees after adjustment for propensity to use hospice, gender, race, enrollment in Medicaid, urban setting, duration of illness, comorbid conditions, low use of Medicare, nursing home residence, and year of death. **RESULTS:** Adjusted mean expenditures were 4.0% higher overall among hospice enrollees than among nonenrollees. Adjusted mean expenditures were 1% lower for hospice enrollees with cancer than for patients with cancer who did not use hospice. Savings were highest (7% to 17%) among enrollees with lung cancer and other very aggressive types of cancer diagnosed in the last year of life. Expenditures for hospice enrollees without cancer were 11% higher than for nonenrollees, ranging from 20% to 44% for patients with dementia and 0% to 16% for those with chronic heart failure or failure of most other organ systems. Hospice-related savings decreased and relative costs increased with age. **CONCLUSION:** Hospice enrollment correlates with reduced Medicare expenditures among younger decedents with cancer but increased expenditures among decedents without cancer and those older than 84 years of age. Future studies should assess the effects of hospice on quality and on expenditures from all payment sources.

PMID: 14970150 [PubMed - indexed for MEDLINE]

8: Br J Cancer. 2003 Dec 15;89(12):2219-26.

Palliative chemotherapy or best supportive care? A prospective study explaining patients' treatment preference and choice.

Koedoot CG, de Haan RJ, Stiggelbout AM, Stalmeier PF, de Graeff A, Bakker PJ, de Haes JC.

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In palliative cancer treatment, the choice between palliative chemotherapy and best supportive care may be difficult. In the decision-making process, giving information as well as patients' values and preferences become important issues. Patients, however, may have a treatment preference before they even meet their medical oncologist. An insight into the patient's decision-making process can support clinicians having to inform their patients. Patients (n=207) with metastatic cancer, aged 18 years or older, able to speak Dutch, for whom palliative chemotherapy was a treatment option, were eligible for the study. We assessed the following before they consulted their medical oncologist: (1) socio-demographic characteristics, (2) disease-related variables, (3) quality-of-life indices, (4) attitudes and (5) preferences for treatment, information and participation in decision-making. The actual treatment decision, assessed after it had been made, was the main study outcome. Of 207 eligible patients, 140 patients (68%) participated in the study. At baseline, 68% preferred to undergo chemotherapy rather than wait watchfully. Eventually, 78% chose chemotherapy. Treatment preference (odds ratio (OR)=10.3, confidence interval (CI) 2.8-38.0) and a deferring style of decision-making (OR=4.9, CI 1.4-17.2) best predicted the actual treatment choice. Treatment preference (total explained variance=38.2%) was predicted, in turn, by patients' striving for length of life (29.5%), less striving for quality of life (6.1%) and experienced control over the cause of disease (2.6%). Patients' actual treatment choice was most strongly predicted by their pre-consultation treatment preference. Since treatment preference is positively explained by striving for length of life, and negatively by striving for quality of life, it is questionable whether the purpose of palliative treatment is made clear. This, paradoxically, emphasises the need for further attention to the process of information giving and shared decision-making.

PMID: 14676798 [PubMed - indexed for MEDLINE]

9: 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.

PMID: 14997074 [PubMed - in process]

10: Can Fam Physician. 2004 Jan;50:27.

Comment on:

Can Fam Physician. 2003 Aug;49:960.
Experienced doctors, be careful what you say.
Hotson K.

Publication Types:

Comment

Letter

PMID: 14761097 [PubMed - indexed for MEDLINE]

11: Can J Anaesth. 2004 Mar;51(3):266-272.

Dying in the ICU: strategies that may improve end-of-life care: [Mourir a l'USI: les strategies qui peuvent ameliorer les soins en fin de vie].

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PURPOSE: Since 10 to 20% of adult patients admitted to the intensive care unit(ICU) in Canada die, addressing the needs of dying critically ill patients is of paramount importance. The purpose of this article is to suggest some strategies to consider to improve the care of patients dying in the ICU. SOURCE: Data sources were randomized clinical trials, observational studies and surveys. We purposively selected key articles on end-of-life care to highlight eight initiatives that have the potential to improve care for dying critically ill patients. These initiatives were presented at the International Consensus Conference on End-of-Life Care in the ICU on April 24-25, 2003 in Brussels,Belgium. Principal findings: We describe eight strategies that, if adopted, may positively impact on the end-of-life care of critically ill patients: 1) promote social change through professional initiatives; 2) legitimize research in end-of-life care; 3) determine what dying patients need; 4) determine what families of dying patients need; 5) initiate quality improvement locally; 6) use quality tools with care; 7) educate future clinicians; and 8) personally engage in end-of-life care. Most of these strategies have not been subjected to rigorous evaluation. CONCLUSION: Adoption of some of these strategies we describe may lead to improved end-of-life care in the ICU. Future studies should include more formal evaluation of the efficacy of end-of-life interventions to help us ensure high quality, clinically relevant, culturally adapted care for all dying critically ill patients.

PMID: 15010412 [PubMed - as supplied by publisher]

12: Crit Rev Oncol Hematol. 2003 Jun;46(3):255-60.

Estimating the costs of caring for the older breast cancer patient.

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As the population ages, it is expected that more and more elderly women will be diagnosed with breast cancer. Relatively little is known about the cost of caring for this group of patients. The goals of this article will be to introduce the relevant types of costs, to review the available data on these costs and to conclude with some thoughts regarding areas for future research.

Publication Types:

Review

Review, Tutorial

PMID: 12791425 [PubMed - indexed for MEDLINE]

13: Fam Med. 2003 Sep;35(8):552-4.

Tuesdays With Morrie: a humanities teaching exercise in palliative and end-of-life care.

Ring JM, Reilly JM.

Family Practice Residency Program, White Memorial Medical Center, 1720 Cesar Chavez Avenue, Los Angeles, CA 90033, USA. ring@usc.edu

PMID: 12947517 [PubMed - indexed for MEDLINE]

14: Fla Nurse. 2003 Dec;51(4):15, 24.

Advance directives for artificial nutrition and hydration. One lesson from the Terry Schiavo case.

Mikos CA, Wilson SM.

Publication Types:

Legal Cases

PMID: 14730803 [PubMed - indexed for MEDLINE]

15: 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 - in process]

16: Gerontologist. 2003 Dec;43(6):808-16.

Two models of caregiver strain and bereavement adjustment: a comparison of husband and daughter caregivers of breast cancer hospice patients.

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PURPOSE: Caregiver bereavement adjustment literature suggests opposite models of impact of role strain on bereavement adjustment after care-recipient death—a Complicated Grief Model and a Relief Model. This study tests these competing models for husband and adult-daughter caregivers of breast cancer hospice patients.

DESIGN AND METHODS: This study used secondary data from the National Hospice Study (Greer & Mor, 1987). Stepwise multiple regression analyses, using caregiver's age and two formulations of prebereavement caregiver role strain as independent variables, predicted grief and despair bereavement adjustment as dependent variables. **RESULTS:** Data from husbands supported a Complicated Grief Model, as greater empirically derived (anxiety and depression symptoms) and theoretically derived (psychological and health strain) caregiver role strain formulations both predicted more difficult bereavement adjustment for husbands.

Neither model was supported for adult daughters, as neither formulation of caregiver role strain predicted daughters' bereavement adjustment. Older caregiver age predicted better bereavement adjustment for both husbands and daughters. Adult daughters experienced more caregiver role strain than husbands did. **IMPLICATIONS:** The family role relationship between caregiver and patient (husband-wife vs. daughter-mother relationship) affects how caregiving factors influence bereavement adjustment.

PMID: 14704380 [PubMed - indexed for MEDLINE]

17: Harv Heart Lett. 2003 Dec;14(4):4.

10 steps for coping with a chronic condition. It pays to organize your approach to heart disease or any chronic medical problem.

[No authors listed]

PMID: 14690985 [PubMed - indexed for MEDLINE]

18: Health Prog. 2004 Jan-Feb;85(1):26-33, 56.
Improving response to life-threatening illness. The nationwide CALL Care project involved 11 Catholic organizations.
McSkimming S, London M, Lieberman C, Geerling E.
Health Services Research, Providence Health System, Portland, OR, USA.
PMID: 14763116 [PubMed - indexed for MEDLINE]

19: Health Prog. 2004 Jan-Feb;85(1):34-7.
Making "caring connections". A new program enhances end-of-life care in a retirement community in Ohio.
Sr Marie Ruegg, Schirm V, Boyce B.
Mission and Health Services, Laurel Lake Retirement Community, Hudson, OH, USA.
PMID: 14763117 [PubMed - indexed for MEDLINE]

20: Health Soc Care Community. 2004 Jan;12(1):43-52.
Carer satisfaction with end-of-life care in Powys, Wales: a cross-sectional survey.
Ingleton C, Morgan J, Hughes P, Noble B, Evans A, Clark D.
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A cross-sectional postal survey of bereaved carers was conducted in order to examine levels of satisfaction with services provided for people in their last year of life in the rural county of Powys, Wales, UK. A self-complete questionnaire, using a modified version of the Views of Informal Carers - Evaluation of Services instrument was sent to all bereaved carers of all those people dying of cancer in Powys between 1 April 1999 and 30 June 2001. Eight hundred and five (out of a possible of 815 people) were contacted and 407 agreed to receive the questionnaire. Out of these 407 individuals, 301 (74% of those who agreed to receive a questionnaire and 37% of the 815 contacted) returned a completed questionnaire. A single reminder letter was sent to non-responders. It was found that the majority of those who received help from district nurses or practice nurses (90%) said that they were excellent or good. However, nearly 40% of respondents reported needing more nursing help. More help was also needed from social care services. For 103 out of the 301 respondents, it was known that the deceased person wanted to die at home; only 44 did so. Only one-fifth of respondents had the opportunity to talk to someone from health and social services after their bereavement; a large majority (four-fifths) found this helpful. One-tenth of respondents reported untreated pain at home; however, there was evidence for an increasing proportion of those treated having received good pain relief. Although there are high levels of satisfaction with care and services received by Powys residents, deficits exist in relation to: symptom control, nursing help, assistance from social services with transport and bathing, communication, and bereavement support.
PMID: 14675364 [PubMed - indexed for MEDLINE]

21: Home Healthc Nurse. 2003 Dec;21(12):833-6.
Respecting the dying patient's rights.
Pitorak EF.
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Patients who are dying have unique needs and special rights. This article discusses eight basic rights for dying patients. It also gives examples of how hospice and home care providers can focus care to respect the dying patient's rights.
PMID: 14665971 [PubMed - indexed for MEDLINE]

22: Intensive Care Med. 2003 Nov;29(11):1895-901. Epub 2003 Oct 07.
Decisions to forgo life-sustaining therapy in ICU patients independently predict hospital death.
Azoulay E, Pochard F, Garrouste-Orgeas M, Moreau D, Montesino L, Adrie C, de Lassence A, Cohen Y, Timsit JF; Outcomerea Study Group.
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OBJECTIVE: More than one-half the deaths of patients admitted to intensive care units (ICUs) occur after a decision to forgo life-sustaining therapy (DFLST). Although DFLSTs typically occur in patients with severe comorbidities and intractable acute medical disorders, other factors may influence the likelihood of DFLSTs. The objectives of this study were to describe the factors and mortality associated with DFLSTs and to evaluate the potential independent impact of DFLSTs on hospital mortality. DESIGN AND SETTING: Prospective multicenter 2-year study in six ICUs in France. PATIENTS: The 1,698 patients admitted to the participating ICUs during the study period, including 295(17.4%) with DFLSTs. MEASUREMENTS AND RESULTS: The impact of DFLSTs on hospital mortality was evaluated using a model that incorporates changes in daily logistic organ dysfunction scores during the first ICU week. Univariate predictors of death included demographic factors (age, gender), comorbidities, reasons for ICU admission, severity scores at ICU admission, and DFLSTs. In a stepwise Cox model five variables independently predicted mortality: good chronic health status (hazard ratio, 0.479), SAPS II score higher than 39 (2.05), chronic liver disease (1.463), daily logistic organ dysfunction score (1.357 per point), and DFLSTs (1.887). CONCLUSIONS: DFLSTs remain independently associated with death after adjusting on comorbidities and severity at ICU admission and within the first ICU week. This highlights the need for further clarifying the many determinants of DFLSTs and for routinely collecting DFLSTs in studies with survival as the outcome variable of interest.
PMID: 14530857 [PubMed - indexed for MEDLINE]

23: Issue Brief Health Policy Track Serv. 2003 Dec 31;:1-19.
Providers issue brief: end of life issues: year end report-2003.
Tanner RC.
Assisted suicide has emerged as one of the most controversial ethical issues in the medical community, and one that is complicated more by technological advances that have allowed people to live longer. But as policymakers debate assisted suicide policy, state lawmakers must also examine ways to improve pain management and end-of-life care for people who suffer from terminal illnesses.
PMID: 14964243 [PubMed - indexed for MEDLINE]

24: J Am Coll Surg. 2004 Feb;198(2):303-19.
Clinical palliative care for surgeons: part 1.
Lee KF, Purcell GP, Hinshaw DB, Krouse RS, Baluss M.
Department of Surgery, Baystate Medical Center, Tufts University School of Medicine, 759 Chestnut Street, Springfield, MA 01199, USA.
PMID: 14759788 [PubMed - indexed for MEDLINE]

25: J Am Med Dir Assoc. 2004 Jan-Feb;5(1):50-4.
CPT coding for hospice in long-term care.

Crossno RJ.
American Board of Hospice and Palliative Medicine, 1904 Sager Road, Rockdale, TX 76567, USA. rcrossno@earthlink.net

PMID: 14706129 [PubMed - indexed for MEDLINE]

26: 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 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.

PMID: 15000054 [PubMed - in process]

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

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

Shugarman LR, Campbell DE, Bird CE, Gabel J, A Louis T, Lynn J.

OBJECTIVE: To examine age, gender, race, and area income differences in Medicare expenditures in the 3 years before death. DESIGN: Cross-sectional study.

PARTICIPANTS: A random sample of aged Medicare beneficiaries who died 1996 to 1999, N = 241,047. MEASURES: We estimate differences in mean Medicare

expenditures by year before death and by age, gender, race, and area income, adjusting for comorbidities and Medicaid enrollment. RESULTS: Expenditures for blacks are lower in the second and third years before death and are not significantly different from whites in the last year of life (LYOL) (y3 = 70%, P <.0001; y2 = 82%, P <.0001; LYOL = 119%, P =.098). Differences in expenditures between decedents with area incomes over \$35,000 compared to under \$20,000 attenuate by the LYOL (y3 = 116%, P <.0001; y2 = 107%, P <.0001; LYOL = 96%, P <.0001).

Expenditure patterns for women versus men vary by age. Among the younger cohorts (68 to 74 and 75 to 79), expenditures are higher for women in all 3 years before death. This difference attenuates among older cohorts; in the oldest cohort (90+), expenditures for men exceed those for women by 11% in the LYOL (P <.0001). Older beneficiaries have higher expenditures in the second and third years before death but lower expenditures in the LYOL. On average, the youngest cohort expended \$8,017 more in the LYOL relative to the oldest cohort, whereas in the third year before death, the oldest cohort's expenditures were \$5,270 more than those for the youngest cohort (P <.0001). CONCLUSIONS: Age-associated differences in aggregate Medicare payments for end-of-life care are more substantial than other differences. The fact that other differences attenuate in the LYOL may reflect having overcome barriers to health care, or reflect an effective ceiling on the opportunities to provide services for persons with overwhelming illness.

PMID: 15009792 [PubMed - in process]

28: J Ky Med Assoc. 2004 Feb;102(2):57-65.

Kentucky's palliative care report card.

Head B, Ritchie CS, Scharfenberger J, Keeney C, Hermann C, Pfeifer M.
University of Louisville Health Sciences Center, Louisville, KY, USA.
Last Acts released the first nationwide evaluation of palliative care services in November 2002. Each state was evaluated or "graded" on the following eight measures: advance care planning policies, location of death, hospice use, hospital end-of-life care services, care in ICUs at the end of life, pain among nursing home residents, state pain policies, and palliative care certified physicians and nurses. Kentucky scored well on state pain policies and number of nurses certified in palliative care but received low grades for hospital services and the number of patient deaths occurring in the home. This manuscript explores Kentucky's deficiencies and accomplishments related to the Last Acts evaluation and addresses opportunities for improving end-of-life care across the Commonwealth.
PMID: 15004936 [PubMed - in process]

29: J Marital Fam Ther. 2003 Oct;29(4):439-53.
Relationships with death: the terminally ill talk about dying.
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This article describes a qualitative study exploring the experiences of terminally ill patients and their families as they lived with the inevitability of death. Frustrated by the dominant discourse surrounding the culture of dying--namely that of Elisabeth Kubler-Ross's stage theory--I sought to revisit the experiences of the terminally ill by talking directly with them. Instead of focusing on how people reacted to the introduction of death into their lives, this research attended to how the dying began relating to life and death differently as a result of death's presence. Through an analysis of ethnographically collected data, the meanings participants constructed around their experiences were explored--culminating in the creation of seven "relationships" that participants shared with death.
PMID: 14593687 [PubMed - indexed for MEDLINE]

30: J Med Ethics. 2003 Dec;29(6):359-63.
Should patient consent be required to write a do not resuscitate order?
Biegler P.
Emergenvy Department, Sandringham Hospital, 193 Bluff Road, Sandringham, Victoria 3191, Australia. pbiegler@bigpond.net.au
Consent ought to be required to withhold treatment that is in a patient's best interests to receive. Do not resuscitate (DNR) orders are examples of best interests assessments at the end of life. Such assessments represent value judgments that cannot be validly ascertained without patient input. If patient input results in that patient dissenting to the DNR order then individual physicians are not justified in overriding such dissent. To do so would give unjustifiable primacy to the values of the individual physician. Therefore patient consent is effectively required to write a DNR order. Patient dissent to a DNR order should trigger a fair process mechanism to resolve the dispute.
PMID: 14662816 [PubMed - indexed for MEDLINE]

31: J Med Ethics. 2003 Dec;29(6):372-3.
Comment on:
J Med Ethics. 2002 Oct;28(5):303-7.

Response to: Increasing use of DNR orders in the elderly worldwide: whose choice is it.
Lawson AD.

Publication Types:

Comment

Letter

PMID: 14662822 [PubMed - indexed for MEDLINE]

32: J Med Ethics. 2003 Dec;29(6):330-6.

When is physician assisted suicide or euthanasia acceptable?

Frileux S, Lelievre C, Munoz Sastre MT, Mullet E, Sorum PC.

Centre for Research in Psychopathology, Mirail University, Toulouse, France.

OBJECTIVES: To discover what factors affect lay people's judgments of the acceptability of physician assisted suicide and euthanasia and how these factors interact. DESIGN: Participants rated the acceptability of either physician assisted suicide or euthanasia for 72 patient vignettes with a five factor design--that is, all combinations of patient's age (three levels); curability of illness (two levels); degree of suffering (two levels); patient's mental status (two levels), and extent of patient's requests for the procedure (three levels).

PARTICIPANTS: Convenience sample of 66 young adults, 62 middle aged adults, and 66 older adults living in western France. MAIN MEASUREMENTS: In accordance with the functional theory of cognition of N H Anderson, main effects, and interactions among patient factors and participants' characteristics were investigated by means of both graphs and ANOVA. RESULTS: Patient requests were the most potent determinant of acceptability. Euthanasia was generally less acceptable than physician assisted suicide, but this difference disappeared when requests were repetitive. As their own age increased, participants placed more weight on patient age as a criterion of acceptability. CONCLUSIONS: People's judgments concur with legislation to require a repetition of patients' requests for a life ending act. Younger people, who frequently are decision makers for elderly relatives, place less emphasis on patient's age itself than do older people.

PMID: 14662811 [PubMed - indexed for MEDLINE]

33: J Palliat Care. 2003 Winter;19(4):263-70.

Place of death and use of health services in the last year of life.

Grande GE, McKerral A, Addington-Hall JM, Todd CJ.

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AIM: To investigate whether health service input in the last year of life differs between cancer patients who die at home versus those dying in inpatient care.

METHODS: Post hoc exploratory case-control study of 127 home deaths and 200 inpatient deaths. Retrospective electronic record linkage of patients' community and inpatient care during the last year of life. RESULTS: Patients who died at home began their home nursing care closer to death than those who died as inpatients. Their first contact with inpatient hospice care began further from death. Before their final month, home death patients also had more specialist and district nursing than patients who died in inpatient care.

CONCLUSIONS: Patients who began their home nursing early were less likely to die at home than those who began such care late. This suggests that it may be difficult to sustain end-of-life care at home for an extended period. Further research incorporating assessment of informal care input and disease trajectory is required to investigate this issue.

PMID: 14959597 [PubMed - indexed for MEDLINE]

34: J Palliat Care. 2003 Winter;19(4):227-8.

When people die alone.... ...A meditation on humanity.

Roy DJ.

Publication Types:

Editorial

PMID: 14959591 [PubMed - indexed for MEDLINE]

35: J Palliat Care. 2003 Winter;19(4):230-7.

Determinants of congruence between the preferred and actual place of death for terminally ill cancer patients.

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A prospective cohort study was conducted to explore the extent of congruence and to identify the determinants of congruence between the preferred and actual place of death of terminally ill cancer patients. A total of 180 terminally ill cancer patients were enrolled (87% response rate) and 127 died during the one-year study period.

Nearly 90% of the subjects preferred to die at home. One-third achieved their preference for place of death. The kappa value of congruence ($\kappa = 0.11$, 95% confidence interval = 0.05-0.17) indicated poor to slight agreement between the preferred and actual place death. Important

determinants of congruence between the preferred and actual place of death for terminally ill cancer patients included rehospitalisation and receiving hospice home care during the final days of life, perceived ability for family to help achieve preferred place of death, and residence in New Haven County. CONCLUSIONS: This study directly confirms that the degree of congruence between the preferred and actual place death is unsatisfactory. Clinical interventions and health policies need to be developed to assist terminally ill cancer patients who may not be able to achieve their preference for place of end-of-life care and death.

PMID: 14959592 [PubMed - indexed for MEDLINE]

36: J Palliat Med. 2004 Feb;7(1):135-43.

Palliative care in the Pueblo of Zuni.

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The American Indian and Alaska Native population is aging and the leading causes of death for those aged 55 and older are chronic diseases such as cancer, heart disease, and the complications of diabetes. There are limited formal palliative care services available to rural and reservation dwelling American Indians and Alaska Natives. This collaboration between a tribally operated home health care agency and a federally operated Indian Health Service hospital, with the support of a palliative care center within an academic medical center, has established a palliative care program in the Pueblo of Zuni. The program is based in the tribal home health agency. Barriers to development included the rural setting with limited professional workforce, competing demands in a small agency, the need for coordination across distinct organizations, and the need to address the

dying process in a culturally proficient manner. Family-focused interviews and other techniques were used to tailor the palliative care program to the unique cultural setting. The program has sought to integrate inpatient care of terminally ill patients at the Indian Health Service (IHS) hospital with outpatient hospice care. The initial goal of obtaining certification as a Medicare Hospice provider has not been met and remains a goal. Meanwhile alternative mechanisms for funding the services have been found. The experience of this collaboration suggests that a tribally based, culturally proficient

palliative care program can be developed within an American Indian/Alaska Native community and that it can drive the local health system toward improved end-of-life care.

PMID: 15000797 [PubMed - in process]

37: J Palliat Med. 2004 Feb;7(1):77-8.

Not always a happy ending: the complexities of the doctor-patient relationship in end-of life care.

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PMID: 15000788 [PubMed - in process]

38: J Palliat Med. 2004 Feb;7(1):39-45.

Trends in opioid use over time: 1997 to 1999.

Tolle SW, Hickman SE, Tilden VP, Bubalo JS, Fromme EK.

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Substantial resources have been spent to improve pain control for dying patients, and increased opioid administration has been presumed. Oregon has been a consistent leading state in per capita use for morphine for the past 10 years, as recorded by the Automation of Reports and Consolidated Orders System (ARCOS). Health policy experts, extrapolating from World Health Organization methods, have suggested these data are indicative of the quality of end-of-life care in Oregon. To determine whether trends in opioid prescription at the state and national levels reflect increased opioid use for inpatients during the final week of life, chart reviews were conducted to record all opioid medications administered in the last week of life to 877 adult inpatients who died from natural causes between January 1, 1997 and December 31, 1999. Inpatient morphine use did not increase significantly for dying patients from 1997 to 1999. However, overall morphine use for both Oregon and the United States as measured by ARCOS data increased significantly. Comparisons revealed no significant difference between linear trends for Oregon and U.S. morphine use, but both were significantly greater than the dying inpatients. This pattern was also found for all other opioids. These findings suggest that ARCOS data do not necessarily provide information about opioid use for specific subpopulations of patients and raise questions about the meaning of observed increases in ARCOS data.

PMID: 15000781 [PubMed - in process]

39: J Palliat Med. 2004 Feb;7(1):80-4.

Death pronouncements: using the teachable moment in end-of-life care residency training.

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INTRODUCTION: Performing death pronouncement and communicating effectively with gathered family is an important skill relevant to end-of-life care. Often it is a responsibility of first-year residents who lack proper training or emotional preparation for the task. Residents' tension about this task presents an opportunity to positively effect their emotions and build skills for providing end of life care in the future. This paper describes a death pronouncement workshop including its

objectives specific to Accreditation Council on Graduate Medical Education (ACGME) competencies, its format and its evolution over 8 years. METHODS: Multiple media and methods are used in the 90-minute workshop for first-year family practice residents including poetry, prose, and narratives on doing death pronouncements by senior residents; reviews and discussion of protocols for death pronouncement, autopsy, and organ donation; and a role-play of a death pronouncement with the opportunity for reflection. RESULTS: Residents consistently provide high ratings for the overall value of workshop. CONCLUSIONS: The death pronouncement workshop serves to prepare residents emotionally to deal with dying patients and provides them the skills to effectively and compassionately communicate with those patients' families while addressing all six ACGME core competencies.

PMID: 15000790 [PubMed - in process]

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

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

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

Publication Types:

Evaluation Studies

PMID: 14689394 [PubMed - indexed for MEDLINE]

41: JAAPA. 2003 Aug;16(8):11, 15-6, 28.

Ars moriendi: the art of dying.

Malespina J.

PMID: 14968489 [PubMed - indexed for MEDLINE]

42: JAAPA. 2003 Aug;16(8):11-2, 15.

Does training in hospice care affect referrals?

Fleming SO.

University of Pittsburgh Medical Center, Shadyside Hospital, Pittsburgh, Pa.,USA.

PMID: 14968488 [PubMed - indexed for MEDLINE]

43: Kans Nurse. 2003 Nov-Dec;78(10):19.

Precepts of palliative care. "Managing nutrition and hydration while providing palliative care".

Kirmer D.

PMID: 14746073 [PubMed - indexed for MEDLINE]

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

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

Volicer L.

Professor of Pharmacology and Psychiatry, Boston University School of Medicine, EN Rogers Memorial Veterans Hospital, Bedford, USA.

Publication Types:

Letter

PMID: 14980528 [PubMed - in process]

45: Med Care. 2004 Feb;42(2):116-22.

Decreasing variation in the use of hospice among older adults with breast, colorectal, lung, and prostate cancer.

Lackan NA, Ostir GV, Freeman JL, Mahnken JD, Goodwin JS.

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BACKGROUND: Utilization of hospice services has been shown to vary by place of residence and patient characteristics. OBJECTIVES: The purpose of this study was to examine whether such variation has changed over time. Hospice utilization is examined as a function of sociodemographic characteristics, geographic location, type of insurance, and year of death. RESEARCH DESIGN: This study used a retrospective cohort design. SUBJECTS: We used data from the linked Surveillance, Epidemiology and End Results (SEER)-Medicare database to study hospice utilization in subjects aged 67 and older diagnosed with breast, colorectal, lung, or prostate cancer from 1991 to 1996 and who died between 1991 and 1999. RESULTS: Of the 170,136 subjects aged 67 and older who died from 1991 through 1999, 51,345 (30.2%) were enrolled in hospice before they died. Hospice utilization varied significantly by patient characteristics, including type of insurance, age, marital status, race and ethnicity, gender, urban versus rural residence, type of cancer, income level, and education level. This variation, however, decreased over time for subgroups defined by type of insurance, marital status, urban residence, and income. Variation in hospice use increased over time as a function of age and type of cancer. There was no change in variation in use in blacks compared with non-Hispanic whites over time. CONCLUSIONS: The variation in hospice use by several patient characteristics is decreasing over time, a finding consistent with the manner in which new medical technologies diffuse.

PMID: 14734948 [PubMed - indexed for MEDLINE]

46: Med Econ. 2003 Dec19;80(24):39.

A peaceful death--side by side.

Thomason SL.

PMID: 14733053 [PubMed - indexed for MEDLINE]

47: Minn Med. 2004 Jan;87(1):8.

Talking to patients about end-of-life care.

Whisnant R.

PMID: 14977261 [PubMed - in process]

48: Minn Med. 2004 Jan;87(1):6.

Minnesota excels in end-of-life care.

Whisnant R.

PMID: 14977259 [PubMed - in process]

49: N Engl J Med. 2004 Feb 19;350(8):840-2; author reply 840-2.

Comment on:

N Engl J Med. 2003 Nov 13;349(20):1943-53.

Opioid therapy for chronic pain.

Klein MJ.

Publication Types:

Comment

Letter

PMID: 14978839 [PubMed - indexed for MEDLINE]

50: N Engl J Med. 2004 Feb 12;350(7):733-4; author reply 733-4.

Comment on:

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

End-of-life care for patients with dementia.

Miller FG.

Publication Types:

Comment

Letter

PMID: 14960754 [PubMed - indexed for MEDLINE]

51: Nephrol Nurs J. 2004 Jan-Feb;31(1):87-8.

Advanced practice in nursing: ethical and role issues in end-of-life care.

Robbins KC.
kcr_nnj@yahoo.com

PMID: 15008080 [PubMed - in process]

52: Nurs Times. 2004 Jan 20-26;100(3):26-7.

'Being there with patients is a privilege'.

Jacques L.

University of Brighton.

PMID: 14963955 [PubMed - indexed for MEDLINE]

53: Nurs Times. 2004 Jan 20-26;100(3):10-1.

DNR case highlights ethical dilemma.

Hartley J.

Publication Types:
Legal Cases

PMID: 14963951 [PubMed - indexed for MEDLINE]

54: Nurs Times. 2004 Jan 13-19;100(2):34-7.

Piloting cross-boundary training to develop cancer care nursing.

Lawther C, Taylor S, Bell A, White H.

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Flexible approaches to lifelong learning have the potential to increase motivation and influence recruitment and retention. This paper explores how the introduction of a collaborative rotational placement programme between the NHS and the voluntary sector helped qualified staff to develop their practice in caring for patients with cancer from diagnosis through to bereavement. Staff experienced an increase in their personal motivation, confidence and enthusiasm.

Publication Types:
Evaluation Studies

PMID: 14768152 [PubMed - indexed for MEDLINE]

55: Palliat Med. 2003 Dec;17(8):688-94.

Professionally perceived effectiveness of psychosocial interventions for existential suffering of terminally ill cancer patients.

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BACKGROUND: Although integrated care for existential suffering is an essential part of palliative care, little is known about its concept and efficacy as perceived by professionals. A questionnaire survey was carried out to 1) explore the underlying structure of psychosocial interventions recommended by specialists, 2) identify the professionally perceived effectiveness of each intervention for specific existential distress, and 3) examine the effects of specialty on their recommendations.

METHODS: A questionnaire with three scenarios representing terminally ill cancer patients with uncertainty-related anxiety, guilt feelings, and dependency-related meaninglessness was mailed to 701 Japanese psychiatrists, 118 psychologists, and 372 palliative care nurses. **RESULTS:** A total of 456 responses were obtained (response rate = 38%). Recommended psychosocial interventions were classified into six subcategories: 'a supportive-expressive approach,' 'providing comfortable environments,' 'meaning-centered approach,' 'being,' 'education and coping skills training,' and 'a religious approach.' A 'supportive-expressive approach' was consistently recommended in all vignettes. On the other hand, 'providing comfortable environments' was most recommended for patients with uncertainty-related anxiety, and a 'meaning-centered approach' and 'being' were most recommended for patients feeling dependency-related meaninglessness. Psychiatrists estimated the effectiveness of psychopharmacological treatment significantly higher than psychologists and nurses, while nurses evaluated efficacy of all other interventions significantly higher than psychiatrists and psychologists. **CONCLUSIONS:** Experts evaluated a variety of clinical interventions as effective in palliating existential suffering, although the perceived levels of efficacy of each intervention differed according to the nature of suffering and their specialties. To effectively alleviate existential suffering in terminally ill cancer patients, an integrated care by an interdisciplinary team is necessary.

PMID: 14694920 [PubMed - indexed for MEDLINE]

56: Pharmacoepidemiol Drug Saf. 2004 Feb;13(2):113-5.

The use of drugs to hasten death.

Deliens L, Ganzini L, Vander Stichele R.

End-of-life Care Research Group, Vrije Universiteit Brussel, Brussels, Belgium.

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PMID: 14998073 [PubMed - in process]

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

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

Gold MF.

PMID: 14677249 [PubMed - indexed for MEDLINE]

58: Psychooncology. 2003 Oct-Nov;12(7):709-19.

Caregiving for women with advanced breast cancer.

Coristine M, Crooks D, Grunfeld E, Stonebridge C, Christie A.

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AIM: To describe the psychosocial impact on caregivers of caring for women with advanced breast cancer. METHODS: Five focus groups were held with bereaved caregivers. Qualitative content analysis of the transcripts was conducted to identify emerging themes. RESULTS: Two categories of caregivers were identified: spouse caregivers (SCGs) and non-spouse caregivers (NSCGs), who were either close friends or relatives. SCGs and the patient managed care cooperatively and shared care-related decision making. Working SCGs managed multiple roles but employers gave them support and freedom to take the time that was necessary to care for their wives. NSCGs had the most life roles to manage, and saw themselves as agents for the patient. The terminal phase of disease was most burdensome for all caregivers, although NSCGs had the most difficulties. During this phase, the patients' activities of daily living became much more impaired. In addition, some patients were not willing to receive continence support from caregivers, and some caregivers found that they could not provide continence support. SCGs were able to negotiate these care-related roles with their spouse, but NSCGs struggled to satisfy the wishes of the patient. CONCLUSION: Caregivers assume great responsibility for providing care, particularly during the terminal phase. Caregiving becomes more complex with each additional life role of the caregiver. SCGs have two advantages: (1) living with the patient facilitates caregiving and (2) patterns of decision making that were established previous to the illness facilitated shared decision making between the patient and spouse caregiver. Copyright 2003 John Wiley & Sons, Ltd.

PMID: 14502595 [PubMed - indexed for MEDLINE]

59: Qual Health Res. 2004 Feb;14(2):204-25.

Family surrogate decision making at the end of life: seeing them through with care and respect.

Meeker MA.

University of Buffalo, New York, USA.

Family surrogate decision makers are pivotal in end-of-life decision-making processes. The author investigated decision-making experiences of 20 surrogates who assisted terminally ill family members for this grounded theory study. Findings describe a basic social process of Seeing Them Through With Care and Respect, during which surrogates continuously synthesized the core values of caring for their family member and respecting their family member's autonomy. Surrogate narratives began with Learning the Diagnosis. The major categories of surrogate decision makers' activities during the process were Standing With and Acting For the ill family member. Events reported in two gating categories, Brokering Information and Working With Family, facilitated or impeded decision making. A final

category, Outcomes, reports consequences for the surrogate of having been a decision maker.

PMID: 14768458 [PubMed - indexed for MEDLINE]

60: 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 - in process]

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

Innovative practices improve end-of-life care.

Canave-Jimenez F. remyj@sprint.ca

PMID: 15005059 [PubMed - in process]

62: Semin Dial. 2003 Sep-Oct;16(5):395-8.

Do not resuscitate orders and iatrogenic arrest during dialysis: should "No" mean "No"?

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An iatrogenic arrest is a cardiopulmonary arrest induced by a therapeutic effort. Frequently cardiopulmonary arrests during hemodialysis (HD) are iatrogenic. In this article I consider the question of what to do when a cardiopulmonary arrest occurs during HD in a patient with a do not resuscitate (DNR) order. I consider and reject four arguments to override the DNR order: the principle of nonmaleficence, the efficacy of resuscitation, proximate cause, and physician error. Instead, I argue that respect for patient autonomy and patient goals means that DNR orders must be respected unless there is compelling evidence that overriding the DNR would be consistent with the patient's goals. If such evidence is lacking, the physician has no moral choice but to follow the DNR order literally. As such, nephrologists need better communication with their patients regarding advance care planning and better documentation of their communication once it has occurred.

PMID: 12969394 [PubMed - indexed for MEDLINE]

63: Support Care Cancer. 2004 Feb 28 [Epub ahead of print]

Differences in physician-reported practice in palliative sedation therapy.

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BACKGROUND. Although palliative sedation therapy is often required in terminally ill cancer patients, little is known about actual practice. The aims of this study were to clarify the physician-reported sedation practices and the factors influencing the sedation rates. **METHODS.** A questionnaire was sent to 105 representative physicians of all certified palliative care units in Japan. A total of 81 responses were analyzed (effective response rate, 80%). **RESULTS.** The prevalence of continuous-deep sedation for physical symptoms was <10% in 33 institutions (41%), 10-50% in 43 institutions (53%), and >50% in 5 institutions (6.2%). The prevalence of continuous-deep sedation for psychoexistential suffering was 0% in 52 institutions (64%), 0.5-5% in 26 institutions (32%) and more than 10% in 3 institutions (3.6%).

Continuous-deep sedation was more frequently performed by physicians who did not believe clear consciousness was necessary for a good death, who did not believe that sedation often shortened patient life, who worked with nurses specializing in cancer/palliative care, who judged the symptoms as refractory without actual trials of treatments, who performed continuous sedation first rather than intermittent sedation, and who used phenobarbitones frequently. **CONCLUSIONS.** Physician-reported practice in palliative sedation therapy varied widely among institutions. The differences were mainly associated with the physicians' philosophy about a good death, physicians' belief about the effects of sedation on patient survival, and physicians' medical practice. Discussion should be focused on these divergent areas, and clear clinical guidelines are urgently needed to provide valid end-of-life care.

PMID: 14991486 [PubMed - as supplied by publisher]

64: Wien Med Wochenschr. 2003;153(17-18):380-4.

Advance directives for psychiatric patients? Balancing paternalism and autonomy.

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Advance directives contain wishes and values, fears and refusals of competent lay people regarding medical interventions in future situations when they might lack communicative and decision-making capacities. However, these advance directives for medical, psychiatric and care interventions can very well be used to improve the care for patients in psychiatry and gerontopsychiatry and to provide individualized care and treatment. The development and use of advance-care documents in psychiatry, and the clinical and ethical appreciation and recognition of the wishes and values of those patients, represent a particularly difficult challenge to medical paternalism.

PMID: 14571662 [PubMed - indexed for MEDLINE]

65: Wien Med Wochenschr. 2003;153(17-18):392-7.

Honouring the age-old commitment to "the patient's good": the promise—and peril--of hospice.

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In this article, the rise of hospice in the United States is examined and some of its important strengths and weaknesses are described. It is suggested that, despite the tendency to believe otherwise, hospice is not immune to a kind of alienation between

patients and clinicians based on the absorption of doctors with biomedical conditions and their possible technological remedies, thus overlooking or ignoring the patient's good. To protect the age-old fiduciary or "trust" relationship between patients and clinicians requires a re-adjustment of current attitudes and practices--not just in the current cure-oriented health care of conventional medicine, but in the palliation-oriented health care of hospice as well. That is, it requires the development of attitudes and practices that foster a democratic, multidisciplinary process of shared decision-making and the adoption of a genuinely bio/psycho/social understanding and articulation of "the patient's good"--irrespective of where along the continuum of care patients and clinicians find themselves (5, 13).
PMID: 14571665 [PubMed - indexed for MEDLINE]