



END OF LIFE CARE BIBLIOGRAPHY September 2004

1: Acad Med. 2004 Aug;79(8):777-82.

Improving knowledge in palliative medicine with a required hospice rotation for third-year medical students.

Porter-Williamson K, von Gunten CF, Garman K, Herbst L, Bluestein HG, Evans W.

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PURPOSE: The Liaison Committee for Medical Education requires accredited U.S. and Canadian medical schools to teach end-of-life care. The purpose of this study was to evaluate a new required curriculum in palliative medicine for third-year medical students. **METHOD:** Beginning in July 2001, a required four-day (32 hour) curriculum was piloted as part of an ambulatory month in the 12-week medicine clerkship. Students spent Day 1 in the classroom learning core concepts regarding hospice, palliative care, and symptom management. A two-hour session with a standardized patient to break bad news was included. Students spent Days 2 and 3 making home visits or participating in inpatient care. Day 4 was spent in the classroom reviewing cases they had seen with interdisciplinary faculty, making presentations on assigned topics, and discussing professional self-care. Students completed a self-awareness project. Educational outcomes were measured with the students' completion of five pre- and postcourse assessment instruments: (1) self-assessment of competency, (2) attitudes, (3) concerns, (4) a 50-item, multiple-choice knowledge test, and (5) an assessment of elements of the course. **RESULTS:** Analysis of 127 paired evaluations showed significant improvements in three instruments: 56% improvement in competence ($p < .0001$), 29% reduction in concern ($p < .0001$), and 23% improvement in knowledge ($p < .0001$). There were no significant changes attitudes ($p = .35$). **CONCLUSION:** This 32-hour required curriculum in palliative medicine for third-year medical students improved knowledge. They came to the course with appropriate attitudes that did not change.

PMID: 15277135 [PubMed - indexed for MEDLINE]

2: Acad Med. 2004 Aug;79(8):760-8.

End-of-life care in the curriculum: a national study of medical education deans.

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PURPOSE: To describe attitudes and practices of end-of-life care teaching in the undergraduate medical curriculum in the United States as reported by administrative leadership and identify opportunities for improvement. **METHOD:** A telephone survey of associate deans for medical education or curricular affairs at a random sample of 62 accredited U.S. medical schools was conducted in 2002. **RESULTS:** Fifty-one deans participated (82% response rate). Most (84%) described end-of-life care education as "very important" and supported incorporating more end-of-life care teaching into the undergraduate curriculum. Sixty-seven percent reported that insufficient time is currently given to palliative care in their curriculum. Although a majority opposed required courses (59%) or clerkships (70%) that focused on end-of-life care, they did unanimously endorse integrating teaching end-of-life care into existing courses or clerkships. Key barriers to incorporating more end-of-life care into the curriculum included lack of time in the curriculum, lack of faculty expertise, and absence of a faculty leader. **CONCLUSION:** Associate deans for medical education or curricular affairs in the United States support integrating end-of-life care content into existing courses and clerkships throughout the undergraduate medical curriculum. Successful integration will require institutional investment in faculty development, including both the development of faculty leaders to drive change efforts, and the education of all faculty who teach students and exert influence as role models and mentors. The strong support for end-of-life care education expressed by academic leaders in this study, combined with the high level of interest expressed in the authors' 2001 national survey of students, provide evidence of the potential for meaningful change in the undergraduate medical curriculum.

PMID: 15277133 [PubMed - indexed for MEDLINE]

3: Acad Med. 2004 Aug; 79(8): 752-7.

An innovative, longitudinal program to teach residents about end-of-life care.

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At the University of California, Irvine Medical Center, an end-of-life curriculum was implemented in 2000 for an internal medicine residency utilizing a longitudinal approach that allowed residents to follow patients through their entire hospice experience. An elective home hospice rotation was developed for which third-year residents served as primary care physicians for patients at the end of life over a one-year period. Residents were supervised by faculty who were hospice medical directors. They also learned through case vignettes, quarterly meetings, textbook reading, and personal projects. From July 2000 to June 2002, residents demonstrated positive attitudes towards hospice care and recommended the rotation highly (mean 8.86 on a scale of 1-10). The rotation grew in popularity from six initial residents to ten residents the next year, and has since become a mandatory rotation for all senior residents. A 360-degree

evaluation uniformly indicated positive resident performance from the hospice team (mean scores 7.56-8.69 on a 1-9 scale), family (mean scores 9.3-9.7 on a 1-10 scale) and faculty (mean scores 7.29-7.72 on a 1-9 scale). Residents were also pleased with the level of teaching (mean 8.86 on a scale of 1-10) and felt that the patient care load was "just right." Their knowledge improved by 8% ($p = .0175$). In conclusion, a longitudinal hospice rotation was implemented that fulfilled curricular goals without undue burden on the residents or residency program.

PMID: 15277130 [PubMed - indexed for MEDLINE]

4: Am Fam Physician. 2004 Jul 15;70(2):343-50.

Comment in:

Am Fam Physician. 2004 Jul 15;70(2):248, 257.

Geriatric failure to thrive.

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In elderly patients, failure to thrive describes a state of decline that is multifactorial and may be caused by chronic concurrent diseases and functional impairments. Manifestations of this condition include weight loss, decreased appetite, poor nutrition, and inactivity. Four syndromes are prevalent and predictive of adverse outcomes in patients with failure to thrive: impaired physical function, malnutrition, depression, and cognitive impairment. Initial assessments should include information on physical and psychologic health, functional ability, socioenvironmental factors, and nutrition. Laboratory and radiologic evaluations initially are limited to a complete blood count, chemistry panel, thyroid-stimulating hormone level, urinalysis, and other studies that are appropriate for an individual patient. A medication review should ensure that side effects or drug interactions are not a contributing factor to failure to thrive. The impact of existing chronic diseases should be assessed. Interventions should be directed toward easily treatable causes of failure to thrive, with the goal of maintaining or improving overall functional status. Physicians should recognize the diagnosis of failure to thrive as a key decision point in the care of an elderly person. The diagnosis should prompt discussion of end-of-life care options to prevent needless interventions that may prolong suffering.

Publication Types:

Review

Review, Tutorial

PMID: 15291092 [PubMed - indexed for MEDLINE]

5: Am J Geriatr Cardiol. 2004 May-Jun;13(3):168-70.

Ethical issues in the management of geriatric cardiac patients.

Library Program Office
Office of Information
Veterans Health Administration

Basta LL; Project GRACE (Guidelines for Resuscitation and Care at End-of-Life).

The University of South Florida, Tampa, FL, USA.

PMID: 15133420 [PubMed - indexed for MEDLINE]

6: Am J Geriatr Psychiatry. 2004 Sep-Oct;12(5):457-72.

End-of-Life Care: Issues Relevant to the Geriatric Psychiatrist.

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Most deaths in the United States occur in the context of chronic diseases in later life and are too often accompanied by potentially remediable emotional or physical suffering. Geriatric psychiatrists and other mental health professionals can contribute meaningfully to the provision of optimal care during the final phases of life. This review provides an overview of end-of-life care, focusing on issues most relevant to the geriatric psychiatrist. The author examined palliative care textbooks and review papers to determine the topics to be included in this article, and searched computerized literature databases on these topics. Many of the recommendations provided herein stem from experts' clinical experience; however empirical evidence is also incorporated and critiqued. Topics covered include conversations with patients and families about end-of-life care; the evaluation and treatment of suffering, including pain, depression, suicidality, anxiety, and delirium; the role of individual and family therapies in caring for dying patients; capacity determination; advance care planning; withholding life-sustaining treatments; and "last resort" (and, in some cases, quite controversial) options, such as terminal sedation, assisted suicide, and euthanasia. The author also notes the relevance of such end-of-life-care considerations to patients with dementia. Geriatric psychiatrists' skills across these multiple domains are of particular usefulness. Through such clinical skills and the application of empirical research tools to the many unanswered questions in the care of dying patients, geriatric psychiatry can make increasingly valuable and visible contributions to improving quality of life for people suffering from life-threatening illnesses.

PMID: 15353384 [PubMed - in process]

7: Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):285-8.

Companion animals in palliative care: stories from the bedside.

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Research has shown that a companion animal or pet can help a person better cope

with stressful life events, prevent loneliness, decrease depression, improve activities of daily living (ADLs), and increase social interactions. Pets in nursing homes have been associated with decreased psychotropic medication usage and a greater than 50 percent reduction in healthcare costs. Despite research in other areas of healthcare, there is limited data concerning the use of companion animals in palliative care. This article presents an overview of companion-animal-associated medical research as well as patient stories that illustrate the roles of companion animals in end-of-life care.

PMID: 15315191 [PubMed - in process]

8: Am J Hosp Palliat Care. 2004 Jul-Aug;21(4):267-74.

Measuring preparedness to address patient preferences at the end of life.

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This study investigated the factor structure of an instrument to measure preparedness perception among Florida licensed clinical social workers for work with elders 'end-of-life care. In a principle component analysis with varimax rotation, three factors were identified with eigenvalues greater than 1.0 and a cumulative variance of 66.982 percent. These factors include: 1) knowledge of end-of-life care, 2) knowledge of resources for elders, and 3) attitude toward elder assisted suicide. The development of this type of instrument may be useful for future research and for determining future educational needs of social workers and other professionals.

PMID: 15315189 [PubMed - in process]

9: Am J Med Sci. 2004 Jul;328(1):37-47.

Integration of palliative care into primary care for human immunodeficiency virus-infected patients.

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Palliative care for patients infected with human immunodeficiency virus (HIV) includes components of pain and symptom management, advance care planning, prioritization of life goals, and the support of individuals and families throughout the entire continuum of the disease. There are numerous social stressors such as stigma, infected family members and caregivers, loss of housing and independent living, and the increasing influence of substance use in all communities. Because many barriers prevent those with advanced disease from getting comprehensive pain and symptom management as well as option planning, it is important for all HIV care providers to improve their knowledge, sensitivity, and competence regarding this aspect of care. This article provides an overview of critical issues in palliative care and information on how best to improve HIV

primary care.

PMID: 15254440 [PubMed - indexed for MEDLINE]

10: Ann Emerg Med. 2004 Mar;43(3):433.

"Do not attempt resuscitation" (DNAR) in the out-of-hospital setting.

[No authors listed]

PMID: 15252947 [PubMed - indexed for MEDLINE]

11: Ann Health Law. 2004 Summer;13(2):365-92, table of contents.

A Dutch perspective: the limits of lawful euthanasia.

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Dutch author Ubaldus de Vries reviews the current state of the euthanasia law in the Netherlands. The legislation, enacted in 2001, creates a medical exception that allows for euthanasia in cases where patients experience "hopeless and unbearable suffering." A brief history of the Dutch approach to euthanasia is set forth, case law is reviewed, and the unique role of the doctor is examined in seeking to understand the extent of one's right to euthanasia in the Netherlands. Because the courts must determine what constitutes "hopeless and unbearable suffering," Professor de Vries analyzes the judicial interpretation of "suffering" and concludes that judicial interpretation has reached its limits, and thus by implication, the limits of lawful euthanasia have been reached.

PMID: 15281482 [PubMed - indexed for MEDLINE]

12: Ann Intern Med. 2004 Aug 3;141(3):236-7.

Comment on:

Ann Intern Med. 2004 Aug 3;141(3):178-85.

Terminal sedation: an acceptable exit strategy?

Gillick MR.

Publication Types:

Comment

Editorial

PMID: 15289225 [PubMed - indexed for MEDLINE]

13: Ann Intern Med. 2004 Aug 3;141(3):178-85.

Comment in:

Ann Intern Med. 2004 Aug 3;141(3):236-7.

Ann Intern Med. 2004 Aug 3;141(3):122.

Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands.

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BACKGROUND: Terminal sedation in patients nearing death is an important issue related to end-of-life care. **OBJECTIVE:** To describe the practice of terminal sedation in the Netherlands. **DESIGN:** Face-to-face interviews. **SETTING:** The Netherlands. **PARTICIPANTS:** Nationwide stratified sample of 482 physicians; 410 responded and 211 of these reported characteristics of their most recent terminal sedation case. **MEASUREMENTS:** Physician reports of frequency of terminal sedation (defined as the administration of drugs to keep the patient in deep sedation or coma until death, without giving artificial nutrition or hydration), characteristics of the decision-making process, drugs used, the estimated life-shortening effect, and frequency of euthanasia discussions. **RESULTS:** Of respondents, 52% (95% CI, 48% to 57%) had ever used terminal sedation. Of the 211 most recent cases, physicians used terminal sedation to alleviate severe pain in 51% of patients (CI, 44% to 58%), agitation in 38% (CI, 32% to 45%), and dyspnea in 38% (CI, 32% to 45%). Physicians reported discussing with patients the decision to use deep sedation in 59% of the 211 most recent cases (CI, 52% to 66%) and the decision to forgo artificial nutrition or hydration in 34% (CI, 28% to 41%). Hastening death was partly the intention of the physician in 47% (CI, 41% to 54%) of cases and the explicit intention in 17% (CI, 13% to 22%) of cases. **LIMITATIONS:** The generalizability of physician reports about their most recent cases to all terminal sedation cases is uncertain. In addition, the findings are subject to recall bias and may not apply to other geographic settings. **CONCLUSIONS:** Terminal sedation precedes a substantial number of deaths in the Netherlands. In about two thirds of most recently reported cases, physicians indicated that in addition to alleviating symptoms, they intended to hasten death.

PMID: 15289214 [PubMed - indexed for MEDLINE]

14: Ann Pharmacother. 2004 Jun;38(6):1015-23. Epub 2004 Apr 30.

Continuous subcutaneous infusion of opiates at end-of-life.

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OBJECTIVE: To review pertinent controlled trials using the continuous

subcutaneous infusion of opioids (CSIO) at end-of-life and offer insight to pharmacists and clinicians into the appropriate use of this route of administration. DATA SOURCES: A MEDLINE search for information regarding the subcutaneous administration of opioids in terminally ill patients (1975-December 2002) was conducted using the key words subcutaneous, narcotics, morphine, hydromorphone, fentanyl, pain, hospices, and palliative care. Additional references were located through review of bibliographies of the articles cited. Case reports and postsurgical studies were excluded. Searches were limited to English-language studies using humans. STUDY SELECTION AND DATA EXTRACTION:

Experimental and observational studies were evaluated, using prospective trials as the evidence base for conclusions and including pertinent retrospective trials as they relate to the subcutaneous infusion of opioids at end-of-life.

DATA SYNTHESIS: CSIO is effective and safe for use in terminal illness.

Appropriate situations for consideration of CSIO are when difficulties arise in using the oral route, standard oral opiate therapy has failed adequate trials, the patient has limited intravenous access, adequate supervision of the CSIO is present, and CSIO will not unduly limit the functional activity of the patient.

CONCLUSIONS: CSIO has a proven role in the management of pain at end-of-life.

CSIO should not be considered the first route for administration of opiates, but does offer distinct advantages in the appropriate setting. CSIO continues to be a choice for end-of-life patients and is gradually becoming a standard practice in palliative medicine.

Publication Types:

Review

Review, Tutorial

PMID: 15122000 [PubMed - indexed for MEDLINE]

15: Arch Intern Med. 2004 Jul 26;164(14):1573-8.

The quality of care plans for patients with do-not-resuscitate orders.

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BACKGROUND: Care plans for patients with do-not-resuscitate (DNR) orders often fail to define limits other than cardiopulmonary resuscitation and fail to address other patient care needs. We studied the explicitness and comprehensiveness of care plans for patients with DNR orders and what factors were associated with this aspect of the quality of their care. METHODS: A cross-sectional study was conducted at Georgetown University Medical Center (GUMC), Washington, DC, and St Vincent Catholic Medical Centers (SVC MC), St Vincent's Hospital-Manhattan, New York, NY. Participants included 189 consecutive medical inpatients with DNR orders. RESULTS: A previously validated medical chart review technique termed concurrent care concerns (CCCs) measured whether 11 possible patient care needs had been addressed within 2 days of the DNR order. Reasons for the DNR order were documented in only 55% of cases, and a consent conversation was documented in only 69%. The mean number of total CCCs per DNR order was 1.55 (1.84 at GUMC and 1.29 at SVC MC; $P = .007$). In a multivariate logistic regression analysis of low (≤ 1) vs high (≥ 2) CCCs,

patients with malignancy ($P = .002$), higher APACHE III (Acute Physiology and Chronic Health Evaluation III) scores ($P = .007$), and a documented consent conversation ($P = .009$) and those at Georgetown ($P = .005$) were more likely to have high attention to CCCs. Patients with dementia were the least likely to have high attention to CCCs. CONCLUSIONS: Documented consent conversations and

care plans for patients with DNR orders are less than ideal. Care plans differ in quality by diagnosis, institution, and whether or not a consent conversation is documented. These observations might help to guide interventions that aim to improve the care of patients with DNR orders.

PMID: 15277292 [PubMed - indexed for MEDLINE]

16: Arch Intern Med. 2004 Jul 26;164(14):1531-3.

Difficult end-of-life treatment decisions: do other factors trump advance directives?

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BACKGROUND: Advance directives are widely promoted as a means to plan for patients' decisional incapacity, yet there is little evidence of their effectiveness. We devised a study to assess physicians' compliance with hypothetical advance directives and further examine their clinical reasoning. METHODS: The study consisted of an analysis of a mailed written survey containing 6 hypothetical cases of seriously ill patients. Each case contained an explicit advance directive with potential conflict between the directive and (1) prognosis, (2) wishes of family or friends, or (3) quality of life. Data were collected on the clinical treatment decisions made by physicians and the reasons for those decisions. Study participants were all internal medicine faculty and resident physicians from a single academic institution. RESULTS: A total of 47% analyzable surveys (117/250) were returned. Decisions by faculty and residents were not consistent with the advance directive in 65% of cases. This inconsistency was similar for faculty and residents (68% and 61%, respectively; $P > .05$). When physicians made decisions inconsistent with the advance directive, they were more likely to list reasons other than the directive for their decisions (89%; $P < .001$). CONCLUSIONS: Internists frequently made treatment decisions that were not consistent with an explicit advance directive. In difficult clinical situations, internists appear to consider other factors such as prognosis, perceived quality of life, and the wishes of family or friends as more determinative than the directive. Future work needs to explore the generalizability of these findings and examine how strictly patients desire their advance directives to be followed.

PMID: 15277284 [PubMed - indexed for MEDLINE]

17: Arch Intern Med. 2004 Jul 26;164(14):1501-6.

Resuscitating advance directives.

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Advance directives have not fulfilled their promise of facilitating decisions about end-of-life care for incompetent patients. Many legal requirements and restrictions concerning advance directives are counterproductive. Requirements for witnessing or notarizing advance directives make it difficult for patients to complete a written directive during a physician visit. State laws that establish a hierarchy of family surrogates for incompetent patients who have not appointed a proxy are inflexible and may not apply to common clinical situations. Advance directives would be more useful if they emphasized discussing end-of-life care with physicians rather than completing a legal document. State laws should be revised to encourage patients to discuss advance directives with physicians and to complete them during an office visit. Such patient-physician discussions about end-of-life care can lead to more informed patient decisions. Procedures for written advance directives should be simplified. Patients should be able to designate health care proxies through oral statements to physicians. These reforms will encourage discussions between patients and physicians about advance directives and may lead to more informed decisions near the end of life.

Publication Types:
Historical Article

PMID: 15277279 [PubMed - indexed for MEDLINE]

18: BMJ. 2004 Aug 28;329(7464):491-4.

Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: before and after study.

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PROBLEM: Despite lack of evidence that enteral feeding tubes benefit patients with dementia, and often contrary to the wishes of patient and family, patients with dementia who have difficulty swallowing or reduced food intake often receive feeding tubes when hospitalised for an acute illness. **DESIGN:** We conducted a retrospective chart review of all patients receiving percutaneous endoscopic gastrostomy or jejunostomy tubes between March and September 2002. **QI**

interventions including a palliative care consulting service and educational programmes were instituted. We conducted a second chart review for all patients receiving feeding tubes between March and September 2003. **SETTING:** 652 bed urban acute care hospital. **KEY MEASURES FOR IMPROVEMENT:** We measured the number of feeding tubes placed in patients with dementia, the number of feeding tubes

placed in patients with dementia capable of taking food by mouth, and the number of feeding tubes placed in patients with dementia with an advance directive stating the wish to forgo artificial nutrition and hydration. STRATEGIES FOR CHANGE: Medical and allied health staff received educational programmes on end of life care and on feeding management of patients with dementia. A palliative care consulting team was established. EFFECTS OF CHANGE: After the interventions, the number of feeding tubes placed in all patients and in patients with dementia was greatly reduced. LESSONS LEARNT: Multidisciplinary involvement, including participation by the administration, was essential to effect change in practice. The intensive focus on a particular issue and rapid change led to "culture shift" within the hospital community. The need to establish unified goals of care for each patient was highlighted. BACKGROUND: A growing body of research over the past decade has questioned the utility of placing feeding tubes (percutaneous endoscopic gastrostomy (PEG) or jejunostomy) in patients with advanced dementia. Studies have found no evidence that feeding tubes in this population prevent aspiration, prolong life, improve overall function, or reduce pressure sores. Additionally, the quality of life of a patient with advanced dementia can be adversely affected when a feeding tube is inserted. The patient may require wrist restraints to prevent pulling on the tube or may develop cellulitis at the gastrostomy site, develop decubitus ulcers, be deprived of the social interaction and pleasure surrounding meals, and require placement in a nursing home. Unfortunately, many doctors are unfamiliar with this literature or face barriers-attitudinal, institutional, or imposed by the healthcare industry-to applying its findings to their practice. Thus feeding tubes are placed in patients who will not benefit from this intervention and whose quality of life in the terminal stage of their illness will be adversely affected. With the expected increase of elderly people with dementia, a great change in doctors' knowledge, attitudes, and practice is necessary to prevent even greater numbers of patients receiving this futile treatment.

PMID: 15331474 [PubMed - in process]

19: BMJ. 2004 Jul 17;329(7458):131.

New penalties proposed for Dutch doctors who flout euthanasia law.

Sheldon T.

Publication Types:

News

PMID: 15258061 [PubMed - indexed for MEDLINE]

20: BMJ. 2004 Jul 17;329(7458):122-3.

Comment on:

BMJ. 2004 Jul 17;329(7458):136.

Compulsion and psychiatry--the role of advance statements.

Thomas P, Cahill AB.

Publication Types:

Comment
Editorial

PMID: 15258044 [PubMed - indexed for MEDLINE]

21: Br J Cancer. 2004 Jul 19;91(2):248-53.

A new quality assurance package for hospital palliative care teams: the Trent Hospice Audit Group model.

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Cancer patients in hospitals are increasingly cared for jointly by palliative care teams, as well as oncologists and surgeons. There has been a considerable growth in the number and range of hospital palliative care teams (HPCTs) in the United Kingdom. HPCTs can include specialist doctors and nurses, social workers, chaplains, allied health professionals and pharmacists. Some teams work closely with existing cancer multidisciplinary teams (MDTs) while others are less well integrated. Quality assurance and clinical governance requirements have an impact on the monitoring of such teams, but so far there is no standardised way of measuring the amount and quality of HPCTs' workload. Trent Hospice Audit Group (THAG) is a multiprofessional research group, which has been developing standards and audit tools for palliative care since the 1990s. These follow a format of structure-process-outcome for standards and measures. We describe a collaborative programme of work with HPCTs that has led to a new set of standards and audit tools. Nine HPCTs participated in three rounds of consultation, piloting and modification of standard statements and tools. The final pack of HPCT quality assurance tools covers: policies and documentation; medical notes review; questionnaires for ward-based staff. The tools measure the HPCT workload and casemix; the views of ward-based staff on the supportive role of the HPCT and the effectiveness of HPCT education programmes, particularly in changing practice. The THAG HPCT quality assurance pack is now available for use in cancer peer review.

PMID: 15213725 [PubMed - indexed for MEDLINE]

22: Br J Nurs. 2004 Jun 24-Jul 7;13(12):722-4.

Confidentiality of patient information when preparing for death.

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Publication Types:

Review

Review, Tutorial

PMID: 15284635 [PubMed - indexed for MEDLINE]

23: Can Respir J. 2004 Jul-Aug;11 Suppl B:7B-59B.

State of the Art Compendium: Canadian Thoracic Society recommendations for the management of chronic obstructive pulmonary disease.

O'Donnell DE, Aaron S, Bourbeau J, Hernandez P, Marciniuk D, Balter M, Ford G, Gervais A, Goldstein R, Hodder R, Maltais F, Road J.

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Chronic obstructive pulmonary disease (COPD) is a common cause of disability and death in Canada. Moreover, morbidity and mortality from COPD continue to rise, and the economic burden is enormous. The main goal of the Canadian Thoracic Society's evidence-based guidelines is to optimize early diagnosis, prevention and management of COPD in Canada. The main message of the guidelines is that COPD is a preventable and treatable disease. Targeted spirometry is strongly recommended to expedite early diagnosis in smokers and former smokers who develop respiratory symptoms, and who are at risk for COPD. Smoking cessation remains the single most effective intervention to reduce the risk of COPD and to slow its progression. Education, especially self-management plans, are key interventions in COPD. Therapy should be escalated on an individual basis in accordance with the increasing severity of symptoms and disability. Long-acting anticholinergics and beta-2-agonist inhalers should be prescribed for patients who remain symptomatic despite short-acting bronchodilator therapy. Inhaled steroids should not be used as first line therapy in COPD, but have a role in preventing exacerbations in patients with more advanced disease who suffer recurrent exacerbations. Acute exacerbations of COPD cause significant morbidity and mortality and should be treated promptly with bronchodilators and a short course of oral steroids; antibiotics should be prescribed for purulent exacerbations. Patients with advanced COPD and respiratory failure require a comprehensive management plan that incorporates structured end-of-life care. Management strategies, consisting of combined modern pharmacotherapy and nonpharmacotherapeutic interventions (eg, pulmonary rehabilitation and exercise training) can effectively improve symptoms, activity levels and quality of life, even in patients with severe COPD.

PMID: 15340581 [PubMed - in process]

24: Clin Oncol (R Coll Radiol). 2004 May;16(3):225-6.

People at the end of life are a vulnerable research population.

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Publication Types:

Library Program Office
Office of Information
Veterans Health Administration

Editorial

PMID: 15191013 [PubMed - indexed for MEDLINE]

25: Compr Ther. 2004 Spring; 30(1):25-36.

Discussing life-sustaining treatments: an overview and communications guide for primary care physicians.

Dugan DO, Gluck EH.

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Physicians must be skilled communicators with patients, families, and multidisciplinary health care teams to meet ethical decision-making challenges arising in end-stage disease care. We offer practical suggestions for collaborative communication in the "perfect storm" of contemporary critical care settings.

Publication Types:

Review

Review, Tutorial

PMID: 15162589 [PubMed - indexed for MEDLINE]

26: Crit Care Med. 2004 Sep; 32(9):1839-43.

A proactive approach to improve end-of-life care in a medical intensive care unit for patients with terminal dementia.

Campbell ML, Guzman JA.

Palliative Care Service (MLC), Detroit Receiving Hospital, and the Divisions of Pulmonary & Critical Care Medicine (JAG) and Internal Medicine (MLC), Wayne State University, Detroit, MI.

OBJECTIVES: : To compare usual care with a proactive case-finding approach for critically ill patients with terminal dementia using an inpatient palliative care service. DESIGN: : Prospective comparison to historical control. SETTING: : Urban, university-affiliated hospital. PATIENTS: : Total of 52 men and women with end-stage dementia, 26 subjects in each control and intervention group. INTERVENTIONS: : Proactive case-finding by the palliative care service was done to offer early assistance to the intensive care unit staff about the treatment of patients with terminal dementia. Results were compared with data obtained retrospectively. MEASUREMENTS AND MAIN RESULTS: : Measurements included age, gender, Acute Physiology and Chronic Health Evaluation Score, Therapeutic Intervention Scoring System, mortality, intensive care unit and hospital lengths of stay, frequency, timing, and goals of do-not-resuscitate orders. The proactive, case-finding approach decreased hospital and medical intensive care unit length of stay. More important, a proactive palliative intervention decreased the time between identification of the poor prognosis and the

establishment of do-not-resuscitate goals, decreased the time terminal demented patients remained in the intensive care unit, and reduced the use of nonbeneficial resources, thus reducing patient burden and the cost of care while having the potential to afford the patient and family increased comfort and psychoemotional support. CONCLUSIONS: : Proactive interventions from a palliative care consultant within this subset of patients improved end-of-life care and decreased use of superfluous resources.

PMID: 15343010 [PubMed - in process]

27: Dimens Crit Care Nurs. 2004 May-Jun;23(3):122-4.

The intimacy of dying: a personal reflection.

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Nurses are often involved in patient care at the patient's end of life. The author describes how a nurse's actions can make a positive difference in one person's life, and in one person's death. Using all of the skills and gifts that nurses have to preserve life is a privilege and a challenge; using all of the skills and gifts nurses have to provide a respectful, dignified, peaceful, and even intimate death, is an equal privilege and challenge.

Publication Types:

Case Reports

PMID: 15192355 [PubMed - indexed for MEDLINE]

28: Eur Respir J. 2004 Aug;24(2):200-5.

Patient-physician communication about end-of-life care for patients with severe COPD.

Curtis JR, Engelberg RA, Nielsen EL, Au DH, Patrick DL.

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Since patients with chronic obstructive pulmonary disease (COPD) infrequently discuss treatment preferences about end-of-life care with physicians, the goal of the present study was to identify which specific areas of communication about end-of-life care occur between patients with severe COPD and their physicians, and how patients rate the quality of this communication. A total of 115 patients with oxygen-dependent COPD, identified in pulmonary clinics in three hospitals and through an oxygen delivery company, were enrolled in this study. A 17-item quality of communication questionnaire (QOC) was administered to patients, along with other measures, including satisfaction with care. The patients reported that most physicians do not discuss how long the patients have to live, what dying might be like or patients' spirituality. Patients rated physicians highly at listening and answering questions. Areas patients rated relatively low

included discussing prognosis, what dying might be like and spirituality/religion. Patients' assessments of physicians' overall communication and communication about treatment correlated well with the QOC. Patients' overall satisfaction with care also correlated significantly with the QOC. In conclusion, this study identifies areas of communication that physicians do not address and areas that patients rate poorly, including talking about prognosis, dying and spirituality. These areas may provide targets for interventions to improve communication about end-of-life care for patients with chronic obstructive pulmonary disease. Future studies should determine the responsiveness of these items to interventions, and the effect such interventions have on patient satisfaction and quality of care.

PMID: 15332385 [PubMed - in process]

29: Fam Pract. 2004 Jun;21(3):310-3.

The needs of patients dying of chronic obstructive pulmonary disease in the community.

Jones I, Kirby A, Ormiston P, Loomba Y, Chan KK, Rout J, Nagle J, Wardman L, Hamilton S.

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BACKGROUND: Ninety percent of the last year of life of a terminally ill patient is spent at home, but possible drawbacks to domiciliary terminal care have been suggested. Most previous studies have taken place in secondary care settings, and have often obtained relatives' views of patients' needs rather than those of the patient. **OBJECTIVES:** Our aim was to determine the needs of patients dying in primary care from chronic obstructive pulmonary disease (COPD). **METHODS:** Semi-structured interviews were undertaken with 16 patients who were having maximal therapy for COPD, who were thought likely to die in the year following the commencement of the study. **RESULTS:** Five themes were identified. (i) Patients' information needs and the future course of their illnesses. Information needs were often variable and patients were sometimes unwilling to contemplate the future. (ii) The impact of symptoms on patients' lives. Dyspnoea was a particular problem. (iii) Attitudes towards and opinions on smoking, which many acknowledged as being causal. (iv) Attitudes to help received. Many patients relied on their family; most patients felt their doctors were helpful although some expressed reservations. (v) Patients' expressed needs. These usually focused on mobility, and many patients would not express needs even when prompted. **CONCLUSION:** Poor symptom control remains an important cause of distress. The low number of expressed needs may reflect patients' unwillingness to appear ungrateful, but the variability of information needs emphasizes the importance of an individual approach to patients with an apparently homogenous disease

PMID: 15128695 [PubMed - indexed for MEDLINE]

30: Fam Pract. 2004 Jun;21(3):282-9.

The incidence and characteristics of end-of-life decisions by GPs in Belgium.

Bilsen J, Stichele RV, Mortier F, Bernheim J, Deliens L.

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BACKGROUND: Medical end-of-life decisions (ELDs) have been discussed for several years in different countries, but little is known about the involvement of GPs in these ELDs. **OBJECTIVES:** The aim of the present study was to establish the incidence and characteristics of ELDs by GPs. **METHOD:** We selected 3999 deaths, a 20% random sample of all registered deaths during the first 4 months of 1998 in Flanders, Belgium, and mailed anonymous questionnaires to the attesting physicians. Here we focus exclusively on the 1647 deaths certified by GPs. **RESULTS:** The GPs returned 1067 questionnaires (response rate of 64.8%). At least one ELD was made in 39.5% [95% confidence interval (CI) 37.8-41.2] of all primary care deaths. The incidence of euthanasia (including physician-assisted suicide) was 1.5% (95% CI 0.9-2.3) (incidence higher among more educated patients and at home), of administration of lethal drugs without the patient's explicit request 3.8% (95% CI 2.9-5.0) (higher among cancer patients), of alleviation of pain and symptoms with possibly life-shortening effect 18.6% (95% CI 17.0-20.2) (higher among cancer patients and married patients) and of non-treatment decisions 15.6% (95% CI 14.2-17.2) (higher among cancer patients and in nursing homes). The decision was not discussed with the patient in three out of four of the ELDs. A colleague was consulted in one in four ELD cases. **CONCLUSION:** ELDs are common in general practice in Flanders, Belgium, despite the restrictive law concerning euthanasia at the time of this study. The incidence of these ELDs varies with cause and place of death, the patient's education and the GP's religion and age. Requirements of prudent practice regarding ELDs are rather poorly met by GPs. Further international research and debate is needed to highlight the GPs' important role in end-of-life care.

PMID: 15128690 [PubMed - indexed for MEDLINE]

31: Geriatr Nurs. 2004 Jul-Aug;25(4):233-7.

Gerontological advance practice nurses: As end-of-life care facilitators.

Henderson ML.

Gerontological advance practice nurses (GAPNs) are ideal providers to assist elderly patients with advanced chronic illness and their families as they experience the final phase of life. The goal of this individualized process is for the patient to experience a "good death"-one that is comfortable and self-determined. This article proposes a model in which the GAPN offers 5 essential services in caring for the patient and family based on their needs and on the principles of end-of-life (EOL) care: 1) assessment of the living situation; 2) symptom management and enhancement of quality of life; 3) advance care planning (ACP); 4) patient and family counseling (emotional, social, spiritual); and 5) continuity, communication, and coordination of care.

PMID: 15311200 [PubMed - in process]

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

Assisted living: aging in place and palliative care.

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

PMID: 15197374 [PubMed - indexed for MEDLINE]

33: Geriatr Nurs. 2004 May-Jun;25(3):133.

Comment on:

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

"Research guiding practices related to cultural issues at end of life".

Dunkley MC.

Publication Types:

Comment

Letter

PMID: 15197370 [PubMed - indexed for MEDLINE]

34: Hastings Cent Rep. 2004 Mar-Apr;34(2):30-42.

Enough. The failure of the living will.

Fagerlin A, Schneider CE.

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In pursuit of the dream that patients' exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned.

PMID: 15156835 [PubMed - indexed for MEDLINE]

35: Hastings Cent Rep. 2004 Mar-Apr; 34(2):9-10.

Like a river.

Neher JO.

Education Valley Medical Center's, Family Medicine Residency, Renton, Washington, USA.

Publication Types:
Case Reports

PMID: 15156830 [PubMed - indexed for MEDLINE]

36: Health Care Food Nutr Focus. 2004 Jul; 21(7):6-7.

The feeding tube.

[No authors listed]

PMID: 15232944 [PubMed - indexed for MEDLINE]

37: Health Prog. 2004 Jul-Aug; 85(4):34-9, 58.

Spiritual care at the end of life. Some clergy lack training in end-of-life care.

Norris K, Strohmaier G, Asp C, Byock I.

Life's End Institute: Missoula Demonstration Project, Missoula, MT, USA.
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PMID: 15314901 [PubMed - indexed for MEDLINE]

38: Health Prog. 2004 Jul-Aug; 85(4):27-33.

Aligning values with practice. The "Promoting Excellence" program demonstrates the practicality of palliative care for patients, families, and caregivers.

Twohig JS, Byock I.

University of Montana, Missoula, USA.

Publication Types:
Case Reports

PMID: 15314900 [PubMed - indexed for MEDLINE]

39: Health Prog. 2004 Jul-Aug;85(4):23-6, 58.

Giving patients a "good death". A New Hampshire facility describes the development of its end-of-life care program.

Mulvihill N.

Covenant Health Systems, Lexington, MA, USA.

PMID: 15314899 [PubMed - indexed for MEDLINE]

40: Health Prog. 2004 Jul-Aug;85(4):12-9, 57.

The ethics of loving care.

Byock I.

Dartmouth Hitchcock Medical Center, Lebanon, NH, USA.

PMID: 15314897 [PubMed - indexed for MEDLINE]

41: Health Serv Res. 2004 Aug;39(4 Pt 1):969-83.

Hospice use by Hispanic and non-Hispanic white cancer decedents.

Lackan NA, Ostir GV, Freeman JL, Kuo YF, Zhang DD, Goodwin JS.

Sealy Center on Aging, University of Texas Medical Branch at Galveston, 77555-0460, USA.

OBJECTIVE: To investigate rates of hospice use between Hispanic and non-Hispanic white Medicare beneficiaries diagnosed with cancer using data from a large, population-based study. DATA SOURCES: Secondary data from the linked SEER-Medicare database including the SEER areas of Los Angeles, San Francisco, and San Jose-Monterey, California, and the state of New Mexico. All subjects were Hispanic or non-Hispanic whites, aged 67 and older, had a cancer diagnosis of breast, colorectal, lung, or prostate cancer from 1991-1996, and died of cancer from 1991-1998. STUDY DESIGN: This study employed a retrospective cohort design to compare rates of hospice use between Hispanics and non-Hispanic whites across patient characteristics and over time. PRINCIPAL FINDINGS: Rates of hospice use were similar for Hispanics (39.2 percent) and non-Hispanic whites (41.5 percent). In a bivariate logistic regression model, Hispanics were significantly less likely to use hospice than non-Hispanic whites (OR 0.91; 95 percent CI 0.85-0.97). However, after adjusting for age, marital status, sex, educational attainment, income, urban versus rural residence, and type of insurance using multivariate logistic regression analysis, the estimated odds for being a hospice user among Hispanics is similar to the odds of being a hospice user among non-Hispanic whites (OR 1.05; 95 percent CI 0.98-1.13).

Stratified analyses revealed significant differences between ethnic groups in the use of hospice by type of insurance and SEER area, indicating interactions between ethnicity and these variables. CONCLUSIONS: Our findings indicate similar rates of hospice use for Hispanics and non-Hispanic whites diagnosed with one of the four leading cancers. Additional studies from other national registries may be necessary to confirm these findings.

PMID: 15230937 [PubMed - indexed for MEDLINE]

42: Health Soc Care Community. 2004 Jul;12(4):283-7.

A delay they can ill afford: delays in obtaining Attendance Allowance for older, terminally ill cancer patients, and the role of health and social care professionals in reducing them.

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Despite a growing interest in holistic care for the terminally ill, financial needs are often not addressed. This is reflected in the fact that some people with a terminal illness are not accessing disability benefits, despite eligibility. The present paper is based on a study investigating delays experienced by cancer patients in obtaining Attendance Allowance (AA) by special rules, and missed opportunities for professionals to assist with claims. The study took place in a hospice where patients were referred to social work professionals for assistance in claiming AA. In each case, the patient had been eligible for some time before the referral. Over a 5-month period, all 22 patients who were referred completed a questionnaire. Data were collected to show their personal characteristics, how they came to be referred for assistance and their level of knowledge of AA. The length of time that people had already been eligible and the time taken to claim were recorded to show the amount of lost benefit. The health and social care professionals whom these patients had seen since becoming eligible were also recorded. A wide range of people experienced delays in accessing AA. Their total lost income ranged from pound 110.60 to pound 1106.00. The median was pound 387.10 and four people died before being awarded AA. Only four patients were fully aware of their eligibility. Every person had seen between one and four professionals since becoming eligible for the benefit, without the meeting resulting in a claim. Increased income aids the management of illness, and information and assistance to claim disability benefits need to be made available in a consistent manner at the earliest opportunity. Health and social care professionals are in a position to provide this. However, changes to the claims process, proposed by the present author, could ensure that AA is received automatically, without delay and without extensive paperwork.

PMID: 15272883 [PubMed - indexed for MEDLINE]

43: Home Healthc Nurse. 2004 May;22(5):341-5.

Artificial nutrition and hydration in end-of-life care. HPNA position paper.

Hospice and Palliative Nurses Association.

Publication Types:
Guideline

PMID: 15131427 [PubMed - indexed for MEDLINE]

44: Home Healthc Nurse. 2004 May;22(5):284.

Nurses in the media: where are home care and hospice?

Humphrey CJ.

Publication Types:
Editorial

PMID: 15131412 [PubMed - indexed for MEDLINE]

45: J Adv Nurs. 2004 Sep;47(6):583-91.

Involvement of nurses in physician-assisted dying.

Bilsen JJ, Vander Stichele RH, Mortier F, Deliens L.

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bilsen j.j.r., vander stichele r.h., mortier f. & deliens l. (2004) Journal of Advanced Nursing47(6), 583-591 Involvement of nurses in physician-assisted dyingBackground. Death in modern societies is often preceded by medical end-of-life decisions. Empirical research on these end-of-life decisions focuses predominantly on the physicians' role. Little is known about the role of other health care workers, especially that of nurses. Aim. This paper reports the findings of a study that investigated how often nurses are consulted by physicians in the decision-making process preceding end-of-life decisions and how often nurses participate in administering lethal drugs in end-of-life decisions. Method. Data were collected within a nationwide cross-sectional retrospective death certificate study in Flanders, the Dutch-speaking part of Belgium. We selected 3999 deaths, a 20% random sample of all those occurring during the first 4 months of 1998. Anonymous questionnaires were mailed to the physicians who signed the death certificates. Several questions concerned the involvement of nurses in end-of-life decisions. Results. We received 1925 valid questionnaires. For all reported end-of-life decisions (39.3% of all deaths in Flanders), physicians provided information about the involvement of nurses. Physicians consulted at least one nurse in 52% of end-of-life decisions cases occurring in institutions, compared with 21.4% of such cases at home. Nurses administered lethal drugs in 58.8% of euthanasia cases occurring in institutions and in 17.2% at home. For cases in which life was ended without the patient's explicit request because, predominantly, they were too ill to do so, these percentages were respectively 82.7% and 25.2%. In institutions, nurses mostly administered drugs without the attendance of a physician who had prescribed the

drugs. Conclusions. Nurses in Belgium are largely involved in administering lethal drugs in end-of-life decisions, while their participation in the decision-making process is rather limited. To guarantee prudent practice in end-of-life decisions, we need clear guidelines, professionally supported and legally controlled, for the assignment of duties between physicians and nurses regarding the administration of lethal drugs to reflect current working practice. In addition, we need appropriate binding standards governing mutual communication about all end-of-life decisions.

PMID: 15324424 [PubMed - in process]

46: J Am Coll Surg. 2004 Aug;199(2):211-5.

Is emergency department resuscitative thoracotomy futile care for the critically injured patient requiring prehospital cardiopulmonary resuscitation?

Powell DW, Moore EE, Cothren CC, Ciesla DJ, Burch JM, Moore JB, Johnson JL.

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BACKGROUND: Documented prehospital asystole justifies termination of resuscitation, but recently it has been proposed to extend this policy to patients in the field with pulseless electrical activity. Consequently, we questioned whether resuscitative thoracotomy is warranted in the critically injured patient who fails to respond to prehospital CPR. **STUDY DESIGN:** A prospective database of all emergency department resuscitative thoracotomies (EDT) performed at our Level I trauma center has been maintained since January 1977. These registry data were augmented by a review of prehospital paramedic records for all survivors of EDT to verify length of CPR. **RESULTS:** During the 26-year study period, 959 patients underwent EDT. Of the 62 patients who survived to leave the hospital, 26 (42%) required prehospital CPR. The injury mechanism in these 26 patients was stab wounds in 18 (69%), gunshot wounds in 4 (15%), and blunt trauma in 4 (15%). The duration of prehospital CPR ranged from 3 to 15 minutes and in 7 patients CPR exceeded 10 minutes. Five survivors had asystole documented at the time of EDT; four of these patients had good functional outcomes at discharge. Each of these patients had pericardial tamponade from ventricular stab wounds. Patients with blunt trauma had uniformly dismal neurologic outcomes. **CONCLUSIONS:** EDT after prehospital CPR can be used to salvage select critically injured patients. Based on these data, we propose that resuscitative thoracotomy is futile care in patients with blunt trauma requiring prehospital CPR longer than 5 minutes, and in patients with penetrating trauma with more than 15 minutes of prehospital CPR. EDT is warranted in those patients with penetrating trauma with less than 15 minutes of prehospital CPR, and should be performed despite documented asystole on arrival if pericardial tamponade is the proximate event.

PMID: 15275875 [PubMed - indexed for MEDLINE]

47: J Clin Forensic Med. 2004 Jun;11(3):133-40.

The end of life decisions -- should physicians aid their patients in dying?

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Decisions pertaining to end of life whether legalized or otherwise, are made in many parts of the world but not reported on account of legal implications. The highly charged debate over voluntary euthanasia and physician assisted suicide was brought into the public arena again when two British doctors confessed to giving lethal doses of drugs to hasten the death of terminally ill patients. Lack of awareness regarding the distinction between different procedures on account of legal status granted to them in some countries is the other area of concern. Some equate withdrawal of life support measures to physician assisted suicide whereas physician assisted suicide is often misinterpreted as euthanasia. Debate among the medical practitioners, law makers and the public taking into consideration the cultural, social and religious ethos will lead to increased awareness, more safeguards and improvement of medical decisions concerning the end of life. International Human Rights Law can provide a consensual basis for such a debate on euthanasia.

Publication Types:

Review

Review, Tutorial

PMID: 15260998 [PubMed - indexed for MEDLINE]

48: J Clin Oncol. 2004 Sep 1;22(17):3581-6.

Survey on use of palliative radiotherapy in hospice care.

Lutz S, Spence C, Chow E, Janjan N, Connor S.

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PURPOSE: Radiation oncologists and hospice professionals both provide end-of-life care for oncology patients, and little has been written about the interface between these two groups of specialists. Hospice professionals were surveyed to assess the perceived need for palliative radiotherapy in the hospice setting, to investigate factors that limit the access of hospice patients to radiotherapy, and to suggest areas of future collaboration on education, research, and patient advocacy. **PATIENTS AND METHODS:** Members of the National Hospice and Palliative Care Organization (NHPCO) and American Society for Therapeutic Radiology and Oncology jointly authored a questionnaire to investigate the beliefs of hospice professionals toward the use of radiotherapy for oncology patients in hospice. The questionnaire was distributed to all NHPCO member institutions, and the results were compiled and statistically analyzed. **RESULTS:** Four hundred eighty of more than 1,800 surveyed facilities responded to the questionnaire. The findings suggest that the majority of hospice professionals feel that radiotherapy is important in palliative oncology and that radiotherapy is widely available in the United States. Yet less than 3% on average of hospice patients served by hospices responding to the survey actually received radiotherapy in 2002. The most common barriers to radiotherapy in

hospice care include radiotherapy expense, transportation difficulties, short life expectancy, and educational deficiencies between the specialties.

CONCLUSION: Multiple barriers act to limit the use of palliative radiotherapy in hospice care. Finding ways to surmount these obstacles will provide opportunity for improvement in the end-of-life care of cancer patients.

PMID: 15337808 [PubMed - in process]

49: J Crit Care. 2004 Mar;19(1):1-9.

Influencing advance directive completion rates in non-terminally ill patients: a systematic review.

Patel RV, Sinuff T, Cook DJ.

Department of Medicine, McMaster University, Hamilton, Ontario, Canada.

PURPOSE: To conduct a systematic review of educational advance care planning interventions directed at patients without terminal illness to determine their influence on the completion rate of advance directives (AD). MATERIALS AND METHODS: We searched MEDLINE; Cochrane Library, and reference lists of all pertinent retrieved articles for randomized trials (RCTs), restricted to English language and adults > or = 18 years. Two investigators independently and in duplicate determined trial eligibility. We included published RCTs evaluating an educational intervention comprised of at least one of; written, audio, or video materials, or direct counseling, and if an outcome included AD completion rate. RESULTS: Nine RCTs (N=3,206) were included. Overall, methodologic quality and reporting transparency were poor. The median composite quality score was 5 (range, 0-10). The odds ratios for AD completion rates ranged from 0.41 to 106.0 across the trials (test of heterogeneity $P < .001$). The summary odds ratio for these educational interventions was 3.71 (95% C.I. 1.46, 9.40). Trials with greater methodologic rigor and reporting transparency produced a more conservative estimate of effect, 2.42 [0.96, 6.10] versus 28.69 [5.08, 162.06] for less rigorous and poorly reported trials ($P = .013$). CONCLUSIONS: Advance directive completion rates documenting patient preferences for end-of-life care may be increased by simple patient-directed educational interventions.

Publication Types:

Review

Review, Academic

PMID: 15100999 [PubMed - indexed for MEDLINE]

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

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

Sherman DW, Matzo ML, Coyne P, Ferrell BR, Penn BK.

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

Publication Types:

Review

Review, Tutorial

PMID: 15201829 [PubMed - indexed for MEDLINE]

51: J Pain Symptom Manage. 2004 Sep;28(3):233-243.

Palliative care units in the netherlands: changes in patients' functional status and symptoms.

Echteld MA, Deliens L, Van Der Wal G, Ooms ME, Ribbe MW.

Institute for Research in Extramural Medicine (EMGO Institute) (M.A.E., L.D., G.v.d.W., M.E.O., M.W.R.), Department of Nursing Home Medicine (M.A.E., M.E.O., M.W.R.), and Department of Social Medicine (M.A.E., L.D., G.v.d.W.), VU University Medical Center, Amsterdam, The Netherlands; Pain Expertise Center (M.A.E.), Erasmus Medical Center, Rotterdam, The Netherlands; and End-of-Life Care Research Group (L.D.), Department of Medical Sociology and Health Sciences, Vrije Universiteit Brussel, Brussels, Belgium.

Although efforts have been made to define optimal terminal care in palliative care units (PCUs), comprehensive longitudinal evaluations of care outcomes in PCUs at the end of life are scarce. In this study, changes in functional status (assistance needed for walking, and toilet use) and symptoms (pain, nausea, shortness of breath, depression, and anxiety) were assessed in all patients (n=355) admitted to 10 PCUs in Dutch nursing homes. Outcomes were measured at 24

hours, 48 hours, one week, and two weeks before death, and at PCU admission. Results show that functional status deteriorated from admission to one week before death, but most symptoms did not worsen in the last three weeks before death. Decreases in pain, anxiety, and nausea were observed. The results suggest that the care provided in the PCUs stabilized the symptom levels. Patients who die between two and four weeks appeared to have more favorable symptom change patterns than patients who die within two weeks, which supports the recommendation to admit eligible patients in earlier phases of their disease. Limitations include the use of proxy measures and some forms of selection bias, which may lead to underestimation of symptom levels.

PMID: 15336335 [PubMed - as supplied by publisher]

52: J Pain Symptom Manage. 2004 Aug;28(2):104-14.

Evaluating palliative care: bereaved family members' evaluations of patients' pain, anxiety and depression.

McPherson CJ, Addington-Hall JM.

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Palliative care surveys often rely on bereaved family members to act as proxies to provide information on patient care at the end of life, after the patient's death. However, when comparing bereaved family members' assessments with those of the patients, agreement is found to be better for symptoms that are more concrete and observable than subjective aspects such as psychological symptoms and pain. To date, little is known about how proxies actually evaluate these types of symptoms. The present study used retrospective verbal protocol analysis to elucidate the thought processes of 30 bereaved relatives during their evaluations of patients' pain, anxiety and depression. The qualitative analysis raised awareness of the difficulties experienced by proxies when discerning the presence of symptoms. It also provided insights into the cues and strategies used when making decisions, contributing to a fuller understanding of how proxies distinguish symptoms. Recommendations are made to improve the design of retrospective palliative care surveys. Copyright 2004 U.S. Cancer Pain Relief Committee

Publication Types:
Evaluation Studies

PMID: 15276191 [PubMed - indexed for MEDLINE]

53: J Pain Symptom Manage. 2004 Aug;28(2):102-3.

Olanzapine-induced delirium in a terminally ill cancer patient.

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

Publication Types:
Case Reports
Letter

PMID: 15276190 [PubMed - indexed for MEDLINE]

54: J Pain Symptom Manage. 2004 Aug;28(2):100-2.

Comment on:
J Pain Symptom Manage. 2003 Sep;26(3):867-75.

Subanesthetic ketamine: an essential adjuvant for intractable cancer pain.

Kotlinska-Lemieszek A, Luczak J.

Publication Types:
Case Reports
Comment
Letter

PMID: 15276189 [PubMed - indexed for MEDLINE]

55: J Palliat Care. 2004 Summer;20(2):113-6.

Family perceptions of clinicians' outstanding practices in end-of-life care.

Cherlin E, Schulman-Green D, McCorkle R, Johnson-Hurzeler R, Bradley E.

Yale University, School of Medicine, Department of Epidemiology and Public Health, New Haven, Connecticut, USA.

PMID: 15332476 [PubMed - in process]

56: J Palliat Care. 2004 Summer;20(2):85-92.

Quality end-of-life care in long-term care facilities: service providers' perspective.

Brazil K, McAiney C, Caron-O'Brien M, Kelley ML, O'Krafka P, Sturdy-Smith C.

Department of Clinical Epidemiology and Biostatistics, McMaster University and St. Joseph's Health System Research Network, Hamilton, Canada.

The goal of this project was to provide guidance on what constitutes quality end-of-life care in long-term care (LTC) facilities. Seventy-nine direct care providers from six LTC facilities participated in 12 focus groups. The focus group discussions examined what made the difference between a "good" death and a "bad" death, and what changes in LTC would improve the care of dying residents. Analyses of the focus group data revealed six themes that contribute to quality end-of-life care in LTC facilities: responding to resident needs, creating a homelike environment, supports for families, providing quality care processes, recognizing death as a significant event, and having sufficient institutional resources. These findings challenge policy makers and providers to consider how to normalize life and death in LTC facilities.

PMID: 15332472 [PubMed - in process]

57: J Palliat Med. 2004 Aug;7(4):558-73.

Jewish Medical Ethics and End-of-Life Care.

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While Judaism espouses the infinite value of human life, Judaism recognizes that all life is finite and, as such, its teachings are compatible with the principles of palliative medicine and end-of-life care as they are currently practiced. Jewish medical ethics as derived from Jewish law, has definitions for

the four cardinal values of secular medical ethics: autonomy, beneficence, nonmaleficence, and justice, with the major difference between Jewish law and secular medical ethics being that orthodox or traditional Jews are perceived to limit their autonomy by choosing, with the assistance and advice of their rabbis, to follow God's law as defined by the Bible and post-Biblical sources. With an understanding of Jewish medical ethics as defined by Jewish law, various issues pertaining to the care of Jewish patients who are near the end-of-life can be better understood. Jewish tradition contains within its textual sources the concept of terminal illness. The shortening of life through suicide, assisted suicide, or euthanasia is categorically forbidden. For patients who are terminally ill, treatments that are not potentially curative may be refused, especially when harm may result. Under certain circumstances, treatments may be withheld, but active treatment already started may not usually be withdrawn. While patients should generally not be lied to regarding their conditions, withholding information or even providing false information may be appropriate when it is felt that the truth will cause significant harm. Pain and suffering must be treated aggressively, even if there is an indirect risk of unintentionally shortening life. Finally, patients may execute advance directives, providing that the patient's rabbi is involved in the process.

PMID: 15353100 [PubMed - in process]

58: J Palliat Med. 2004 Aug;7(4):533-44.

"Getting Everyone on the Same Page": Nursing Home Physicians' Perspectives on End-of-Life Care.

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PURPOSE: To improve understanding of nursing home physicians' perspectives regarding end-of-life care, and to suggest directions for further research. **METHODS:** An exploratory qualitative design based on interviews of 12 nursing home physicians, 10 of whom were medical directors. Medical students served as interviewers. **SAMPLE:** A purposeful sampling strategy yielded interviews with 12 physicians. The sample was selected based on "intensity sampling," which seeks information-rich but not extreme cases. Ten of the 12 physicians were nursing home medical directors; all respondents practiced at least 4 years part-time or full-time in a nursing home setting. Respondents varied by age, gender, urban/rural location, and fellowship training (half the sample had completed a geriatrics fellowship). Seven physicians were affiliated with an academic medical center. **RESULTS:** Four themes were identified in the analysis of the 12 interview transcripts: extensive familiarity with dying; consensus is integral to good end-of-life care; obstacles can interfere with consensus; and advance directives set the stage for conversations about end-of-life care. The importance of consensus, both in terms of prognosis and in developing a palliative care plan, emerged as the major finding. **CONCLUSIONS:** For the 12 physicians in this study consensus about the resident's status and an appropriate care plan are important features of good end-of-life care. Further research is needed to determine if other members of the health care team (i.e., residents, family members, nursing staff, social worker, etc.) also value consensus highly. It will be important to determine what barriers to consensus other team members identify. Based on the understanding generated from this

study, a refinement of the general Education for Physicians on End-of-Life Care (EPEC) model describing the relationship between curative and palliative care is proposed for nursing homes. The refinement underscores the points at which the team might consider revisiting consensus about the resident's status and care plan.

PMID: 15353097 [PubMed - in process]

59: J R Soc Med. 2004 Sep;97(9):428-31.

Community hospitals: an under-recognized resource for palliative care.

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In the UK there are concerns that, in certain groups of dying patients such as the old, those with non-cancer diagnoses and those in rural areas, the quality of care is unacceptably variable. There has been no systematic survey of the extent to which community hospitals provide general palliative care for such patients. Therefore, by means of a structured questionnaire we asked senior nurses/managers at all 478 community hospitals in the UK for information on staff expertise, facilities and specialist equipment, liaison arrangements with specialist palliative care providers, priorities, practice and policy in end-of-life care. Of the 346 hospitals (72%) that responded, only 28 were in urban areas. 73% of hospitals employed at least one nurse with additional training in palliative care, 72% had access to 24-hour specialist palliative care advice and 51% had separate overnight accommodation for relatives, but only 22% had designated palliative care beds. Most hospitals did not have written policies or guidelines for patient assessment or symptom control. These findings add to evidence that community hospitals represent an important resource to improve access to palliative care for groups that are currently under-served.

PMID: 15340022 [PubMed - in process]

60: J Trauma. 2004 Jul;57(1):37-41.

Futility of resuscitation criteria for the "young" old and the "old" old trauma patient: a national trauma data bank analysis.

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BACKGROUND: Increasing geriatric trauma is producing disproportionate use of resources. In burn victims, age and burn extent correlate with mortality, yielding the establishment of criteria for futile resuscitation. Such criteria would be useful to trauma patients and their families in making withdrawal-of-care decisions while reducing resource use. Our objective,

therefore, was to identify injury and physiologic parameters that would indicate a high probability of futile resuscitation among geriatric trauma patients. METHODS: Data pertaining to patients greater than or equal to 65 years of age within the National Trauma Databank from 1994 to 2001 were analyzed. Multivariate logistic regression-with mortality as the outcome variable and head, chest, and/or abdominal injury; base deficit; gender; comorbidities; and admission systolic blood pressure (SBP) as covariates-was performed to develop a stratification scheme providing criteria indicative of a high probability of futile resuscitation. RESULTS: There were 76,304 patients with a mean age of 79.4 years. Head, thoracic, and abdominal injury; age; gender; comorbidities; admission SBP; and base deficit were associated with mortality. Patients with severe chest and/or abdominal injury, moderate to severe head injury, admission SBP less than 90 mm Hg, and significant base deficit had mortalities approaching 100%. Older patients with modest shock and mild to moderate head injury admitted with severe chest and/or abdominal injury had a less than 5% chance of survival. CONCLUSION: Geriatric trauma patients with severe chest and/or abdominal trauma with moderate shock and mild to moderate head injury have an exceedingly low probability of survival. These data support early withdrawal of care in these individuals.

PMID: 15284545 [PubMed - indexed for MEDLINE]

61: Mil Med. 2004 Jun;169(6):433-6.

Advance directives and do-not-resuscitate orders on general medical wards versus the intensive care unit.

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The records of 335 patients admitted to the general medicine wards and to the medical intensive and coronary care unit (MICCU) at Brooke Army Medical Center were retrospectively reviewed to assess the frequency of advance directives and "do not resuscitate" (DNR) designations. Two hundred sixty-seven (79.7%) were admitted to the ward and 68 (20.3%) were admitted to the MICCU. Advance directives were executed in 14.9% of patients. DNR designations were made for 21 (7.9%) patients on the ward and 11 (16.2%) patients in the MICCU ($p = 0.064$). There were no statistical differences in mean length of stay, presence of advance directives, or documentation of advance directives in ward versus MICCU patients. However, there was a statistical difference in the number of deaths in the MICCU as compared with that on the ward (9.7 vs. 2.7%, $p < 0.05$). The frequency of advance directives and DNR designations did not differ between ward and MICCU patients in this population, although there was a trend for greater DNR designations in the MICCU environment.

PMID: 15281671 [PubMed - indexed for MEDLINE]

62: N Engl J Med. 2004 Aug 26;351(9):912-22.

Case records of the Massachusetts General Hospital. Weekly clinicopathological

exercises. Case 27-2004. A 79-year-old woman with disturbances in gait, cognition, and autonomic function.

Schlossmacher MG, Hamann C, Cole AG, Gonzalez RG, Frosch MP.

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Publication Types:

Case Reports

Clinical Conference

PMID: 15329430 [PubMed - indexed for MEDLINE]

63: Nurs Ethics. 2004;11(4):349-65.

Nurses' attitudes to euthanasia: a review of the literature.

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This article provides an overview of the scarce international literature concerning nurses' attitudes to euthanasia. Studies show large differences with respect to the percentage of nurses who are (not) in favour of euthanasia. Characteristics such as age, religion and nursing specialty have a significant influence on a nurse's opinion. The arguments for euthanasia have to do with quality of life, respect for autonomy and dissatisfaction with the current situation. Arguments against euthanasia are the right to a good death, belief in the possibilities offered by palliative care, religious objections and the fear of abuse. Nurses mention the need for more palliative care training, their difficulties in taking a specific position, and their desire to express their ideas about euthanasia. There is a need to include nurses' voices in the end-of-life discourse because they offer a contextual understanding of euthanasia and requests to die, which is borne out of real experience with people facing death.

Publication Types:

Review

Review, Academic

PMID: 15253571 [PubMed - indexed for MEDLINE]

64: Nurs Stand. 2004 Jul 21-27;18(45):14-5.

Easing the pain.

Wallis L.

PMID: 15356901 [PubMed - indexed for MEDLINE]

65: Nurs Stand. 2004 Jun 30-Jul 6;18(42):12-3.

A voice of reason.

Leifer D.

Publication Types:

Legal Cases

PMID: 15317347 [PubMed - indexed for MEDLINE]

66: Nurs Times. 2004 Jul 6-12;100(27):12-3.

Protecting vulnerable patients.

O'Dowd A.

PMID: 15317255 [PubMed - indexed for MEDLINE]

67: Palliat Med. 2004 Jul;18(5):468-77.

The end of life: informal care for dying older people and its relationship to place of death.

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OBJECTIVE: This study examined the features of informal end-of-life care of older people living in the community and the association between informal care characteristics and dying at home. **METHODS:** Retrospective data were obtained from interviews and self-administered questionnaires of 56 persons who had been primary caregivers of older relatives in the last three months of their lives. **RESULTS:** Results showed that informal caregivers of terminally ill older people living in the community provided a considerable amount of personal, household, and management care. Secondary informal caregivers and formal caregivers assisted resident primary caregivers less often than nonresident primary caregivers. Primary caregivers who felt less burdened, who gave personal care more intensively, and/or who were assisted by secondary caregivers, were more likely to provide informal end-of-life care at home until the time of death. **CONCLUSIONS:** Our study showed that informal care at the end of life of older people living in the community is complex, since the care required is considerable and highly varied, and involves assistance from secondary informal caregivers, formal home caregivers as well as institutional care. Burden of informal care is one of the most important factors associated with home death. More attention is needed to help ease the burden on informal caregivers, specifically with regard to resident caregivers and spouses. Since these resident caregivers were disadvantaged in several respects (i.e., health, income, assistance from other carers) compared to nonresident caregivers,

interventions by formal caregivers should also be directed towards these persons, enabling them to bear the burden of end-of-life care.

PMID: 15332425 [PubMed - in process]

68: Psychosomatics. 2004 Jul-Aug;45(4):311-8.

Association between clinician factors and a patient's wish to hasten death: terminally ill cancer patients and their doctors.

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This study investigated the clinical factors associated with a wish to hasten death among patients with advanced cancer receiving palliative care, with a focus on the role of clinician-related factors. Patients were grouped into high- and low-scoring groups on the basis of their wish to hasten death; doctor-patient pairs were formed. Questionnaire data collected from patients and their treating doctors were subjected to multivariate analysis. Significant predictors of a high wish to hasten death in terminally ill patients from among treating clinicians included the clinician's perception of the patient's lower optimism and greater emotional suffering, the patient indicating a wish to hasten death, the doctor willing to assist the patient in hastening death (if requested and legal), and the doctor reporting less training in psychotherapy. When these variables were combined with patient factors identified in a previous study, the model significantly predicted a wish to hasten death with the following variables-patient factors: a higher perceived burden on others, higher depressive symptom scores, and lower family cohesion; physician factors: the doctor willing to assist the patient in hastening death (if requested and legal), the doctor's perception of lower levels of optimism and greater emotional distress in the patient, and the doctor having less training in psychotherapy; and the setting of care: recent admission to a hospice. The findings support the multifactorial influences on the wish to hasten death and suggest that the role of the clinician is a vital context within which the wish to hasten death should be considered.

PMID: 15232045 [PubMed - indexed for MEDLINE]

69: Semin Oncol Nurs. 2004 May;20(2):121-39, table of contents.

Consensus statements, positions, standards, and guidelines for pain and care at the end of life.

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Standards, guidelines, and position and consensus statements by themselves do not change practice or improve pain management and care at the end of life. However, if they are used effectively, they support best practices, provide a

forum for discussion of current recommendations, and provide nurses with the latest science and information to advocate for effective pain and symptom management.

PMID: 15253595 [PubMed - indexed for MEDLINE]

70: Semin Oncol Nurs. 2004 May;20(2):74-88, table of contents.

Promoting professional oncology nursing practice through position papers.

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The position papers discussed in this article emphasize issues that relate to the clinical practice of oncology nursing and focus on promoting nursing roles, decreasing barriers to nursing practice, and address issues pertinent to nursing education and research. Position papers are not only helpful for advocating policy change with government and regulatory bodies, but nurses can use them to directly improve their work environments.

PMID: 15253591 [PubMed - indexed for MEDLINE]

71: Urol Nurs. 2004 Jun;24(3):217, 221.

Finding joy in the journey.

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PMID: 15311495 [PubMed - indexed for MEDLINE]