



## **END OF LIFE CARE BIBLIOGRAPHY FEBRUARY 2004**

1: Am J Hosp Palliat Care. 2004 Jan-Feb;21(1):67-8.

Annie's song: a student's reflection on a memorable patient's end-of-life care.

Norton C, Thacker A.

Georgetown University, School of Nursing and Health Studies, Washington, DC, USA.

PMID: 14748527 [PubMed - in process]

2: Am J Hosp Palliat Care. 2004 Jan-Feb;21(1):28-32.

Cultural competence in hospice.

Doorenbos AZ, Schim SM.

College of Nursing, Michigan State University, East Lansing, Michigan, USA.

Research shows that ethnic minorities access hospice care significantly less often than Caucasians. In part, this has been attributed to the lack of cultural competence among hospice staff. To assess cultural competence among hospice workers, this article evaluates the results of a descriptive, exploratory survey that was submitted to 125 interdisciplinary hospice employees and completed by 113 of those employees. Cultural-competence behavior scores varied widely based on two factors: increased education and previous cultural-diversity training. The results of this study provide information regarding cultural competence in hospice. In their efforts to provide culturally appropriate end-of-life care, hospices can use the information in this study to implement intervention plans aimed at increasing cultural competence among hospice staff.

PMID: 14748520 [PubMed - in process]

3: Am J Hosp Palliat Care. 2004 Jan-Feb;21(1):19-27.

Palliative care at the end of life: comparing quality in diverse settings.

Paice JA, Muir JC, Shott S.

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Chicago, Illinois, USA.

There is growing awareness that pain and other symptoms are often poorly managed at the end of life. The purpose of this quality improvement project was to compare the quality of care provided to a convenience sample of 195 patients who died during a six-month period, using a retrospective chart review. Quality was defined by symptom documentation, use of diagnostic and therapeutic procedures in the final 48 hours of life, and determination of advance directives. Daily and total charges incurred by these patients were also captured. Symptom distress was common, and diagnostic and therapeutic procedures were widespread. These data suggest areas for improvement in clinical practice, in palliative care units, and in all settings where end-of-life care is provided. Also, the data can guide future research into the quality of care provided to dying persons.

PMID: 14748519 [PubMed - in process]

4: Am J Hosp Palliat Care. 2004 Jan-Feb;21(1):33-9.

Sexuality at the end of life.

Stausmire JM.

Mercy College of Northwest Ohio, Oregon, Ohio, USA.

There is very little research literature that addresses sexuality at the end of life. Although end-of-life care has become a priority for nursing education, the issue of end-of-life sexuality is not included in the curriculum. Nurses are frequently in a position to establish relationships with couples that encourage a frank discussion and information sharing. As patient advocates, nurses can address end-of-life sexuality issues by taking a sexual history and implementing a general intervention model, such as the PLISSIT. Couples need to be reassured that if they have enjoyed a close sexual relationship, sexual intimacy may continue to be part of their relationship, even at the end of life.

PMID: 14748521 [PubMed - in process]

5: Am J Hosp Palliat Care. 2003 Nov-Dec;20(6):448-58.

The Ohio Hospice Bereavement Study: meeting NHPCO standards.

Rathbun A, Denham SA, McCarthy CC.

Ohio University, Athens, Ohio, USA.

Little attention has been paid to documenting the quality and impact of hospice bereavement programs. While quality of life, quality of dying, and quality of end-of-life measures are common indicators of effective clinical service, they are not

adequate gauges of quality from a bereavement perspective. The National Hospice and Palliative Care Organization (NHPCO) published standards for hospice and palliative care programs that included a section on bereavement care. Little evaluative work has been done to discover whether hospice programs nationwide are compliant with these standards. The purpose of this study was to evaluate whether hospice programs (n = 32) in the state of Ohio were meeting the NHPCO bereavement standards. Findings indicated that the participating hospice programs were 83 percent compliant at least some of the time.

Publication Types:  
Evaluation Studies

PMID: 14649562 [PubMed - indexed for MEDLINE]

6: Am J Hosp Palliat Care. 2003 Nov-Dec;20(6):441-6.

On projective identification, containment, and feeling special: some thoughts about hospice nurses' experiences.

Jones A.

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This discussion is derived from a qualitative research study that examined the benefits of small group supervision for hospice nurses. Sigmund Freud's beliefs about early human development, Melanie Klein's theories of projective identification, and the later developments by Wilfred Bion concerning the container and contained, form a framework for understanding events. Alternative ideas are drawn from early psychoanalytic research with nurses. Individual comments from hospice nurses illustrate the profundity of working with issues of serious illness, while the work of a hospice nurse is illustrated with a single clinical narrative. The discussion poses questions rather than offering answers to the complexities of human service. It shows how some people throughout the event of serious illness may signal their readiness to make important changes in their lives or, conversely, intensify normal unhelpful modes of communicating with others. With the support of other members of the team, a hospice nurse was able to help a man ill with cancer to decide how to live the brief life that was left to him and make closer relationships. Thoughtful work discussions also seem to offer much to hospice nursing practices in the way of learning and support.

Publication Types:  
Case Reports

PMID: 14649561 [PubMed - indexed for MEDLINE]

7: Am J Hosp Palliat Care. 2003 Nov-Dec;20(6):434-40.

Job satisfaction among hospice interdisciplinary team members.

DeLoach R.

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The purpose of this study was to investigate job satisfaction among hospice interdisciplinary team (IDT) members. Interdisciplinary team members (N = 76) from several hospices in Ohio participated in the study. Pearson product-moment correlations ( $p < .05$ ) revealed that there were significant relationships between job satisfaction and autonomy, role ambiguity, role conflict, supervisory support, task significance, routinization, positive affectivity, negative affectivity, and team functioning. Multiple regression analysis ( $p < .05$ ) revealed that supervisory support, positive affectivity, role ambiguity, autonomy, and routinization were significant predictors of job satisfaction.

PMID: 14649560 [PubMed - indexed for MEDLINE]

8: Am J Hosp Palliat Care. 2003 Nov-Dec;20(6):475-6.

Wind of grace.

Turner S.

Hospice of Central Montana, Lewistown, Montana, USA.

Publication Types:  
Case Reports

PMID: 14649566 [PubMed - indexed for MEDLINE]

9: Am J Hosp Palliat Care. 1990 Nov-Dec;7(6):39-42.

Pain control in hospice home care: management guidelines.

Crane RA, Wilson PC, Behrens G.

The Blessing Hospice, Quincy, Illinois, USA.

PMID: 14686472 [PubMed - indexed for MEDLINE]

10: Am J Hosp Palliat Care. 1990 Nov-Dec;7(6):43-5.

Patients' perceptions of a community volunteer support program.

McGill A, Wares C, Huchcroft S.

Tom Baker Cancer Centre, Calgary, Alberta, Canada.

PMID: 14686473 [PubMed - indexed for MEDLINE]

11: Am J Kidney Dis. 2003 Oct;42(4):813-20.

The need for end-of-life care training in nephrology: national survey results of nephrology fellows.

Holley JL, Carmody SS, Moss AH, Sullivan AM, Cohen LM, Block SD, Arnold RM.

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Because of the high mortality rate of end-stage renal disease, nephrologists care for many dying patients. However, the education of nephrology fellows in palliative care has not been assessed. We surveyed second-year nephrology fellows to assess the quantity and quality of teaching they received in palliative medicine and also asked about their preparedness to manage patients at the end of life. A 63% survey response rate yielded 173 surveys for evaluation. Nearly all fellows (99%) agreed that physicians have a responsibility to help patients at the end of life; half thought it was very important to learn how to care for dying patients. On a 10-point scale in which

0 is no teaching and 10 is a lot of teaching, fellows reported significantly less teaching in end-of-life care (mean score, 3.8 +/- 2.6) than in managing a patient with distal renal tubular acidosis (mean score, 6.3 +/- 2.5) or on hemodialysis therapy (mean score, 8.9 +/- 1.5; all  $P < 0.0001$ ). Specific palliative care content areas were taught infrequently; only 22% of fellows were taught how to tell a patient he or she is dying. Fellows who had contact with a palliative care specialist reported more education on end-of-life issues and believed they were better prepared to provide such care. Fellows' palliative care experiences during fellowship frequently occurred without attending nephrologist supervision; 32% of fellows had conducted 2 or fewer family meetings, and 26% of all family meetings occurred without an attending nephrologist. Fellows believed they were best prepared to manage a patient on hemodialysis therapy (mean score, 8.9 +/- 1) and least prepared to manage a patient at the end of life (mean score, 6.1 +/- 2;  $P < 0.0001$ ). Our results show that most nephrology fellows believe they should learn how to care for dying patients, but most fellowship programs do not offer this training. Our study therefore suggests that training in palliative care be incorporated into fellowship program curricula.

PMID: 14520633 [PubMed - indexed for MEDLINE]

12: Am J Kidney Dis. 2003 Aug;42(2):217-28.

Comment in:

Am J Kidney Dis. 2003 Aug;42(2):385-7.

Analgesia in patients with ESRD: a review of available evidence.

Kurella M, Bennett WM, Chertow GM.

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Moderate to severe pain frequently accompanies chronic diseases in general and end-stage renal disease (ESRD) in particular. Several analgesic agents and associated metabolites show altered pharmacokinetics in the presence of reduced glomerular filtration rate. Drug-related side effects may exacerbate symptoms frequently observed in persons with chronic kidney disease (CKD; eg, fatigue, nausea, vomiting, and constipation) or those often attributed to hemodialysis therapy (eg, orthostatic hypotension and impaired cognition). Persons with advanced CKD and ESRD are at increased risk for adverse effects of analgesic agents because of enhanced drug sensitivity, comorbid conditions, and concurrent medication use. Dose adjustment and avoidance of certain analgesics may be required in patients with advanced CKD and ESRD. We review the available evidence on pharmacokinetics and adverse drug effects of various analgesic agents commonly used in patients with advanced CKD and ESRD. Determining an optimal approach to the control of pain in patients with advanced CKD and ESRD will require additional research.

Publication Types:

Review

Review, Tutorial

PMID: 12900801 [PubMed - indexed for MEDLINE]

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

End-of-life care of older adults.

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Publication Types:

Case Reports

Review

Review, Tutorial

PMID: 14625425 [PubMed - indexed for MEDLINE]

14: Ann Acad Med Singapore. 2003 Nov;32(6):785-9.

End-of-life care: challenges and obligations in setting limits to life-sustaining therapy.

Lee AO.

Department of Geriatric Medicine, Tan Tock Seng Hospital, 11 Jalan Tan Tock Seng, Singapore 308433.

It is now generally accepted that the withholding or withdrawal of interventions that serve only to prolong the dying process is appropriate. Setting limits to life-sustaining therapy are now common practice. However, making such decisions can

be challenging. They are also not uncommonly a source of disagreement between the physician and the patient or surrogate. The potential for strained patient-physician relationship can be mitigated by patient-centred, goal-specific care with its emphasis on effective communication, a sense of timing and attention to the various dimensions of the illness experience.

PMID: 14716947 [PubMed - in process]

15: Ann Intern Med. 2004 Jan 6;140(1):70-1; author reply 71.

Comment on:

Ann Intern Med. 2003 Feb 18;138(4):335-7.

Hospice benefits and phase I cancer trials.

Trump DL.

Publication Types:

Comment  
Letter

PMID: 14706985 [PubMed - indexed for MEDLINE]

16: Ann Intern Med. 2004 Jan 6;140(1):70; author reply 71.

Comment on:

Ann Intern Med. 2003 Feb 18;138(4):335-7.

Hospice benefits and phase I cancer trials.

Avery R.

Publication Types:

Comment  
Letter

PMID: 14706984 [PubMed - indexed for MEDLINE]

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

Dying with advanced dementia in the nursing home.

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BACKGROUND: Nursing homes are important providers of end-of-life care to persons with advanced dementia. METHODS: We used data from the Minimum Data Set

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

PMID: 14769629 [PubMed - in process]

18: Br J Nurs. 2003 Sep 25-Oct 8;12(17):1038-42.

Do not attempt resuscitation decisions: the nursing role.

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This exploratory study examines the roles of practice nurses with regard to do not attempt resuscitation (DNAR) decisions. The British Medical Association (BMA) and the Royal College of Nursing (RCN) have published joint DNAR guidelines. One NHS trust responded by developing a local DNAR policy written for use in hospital and general practice. The study focuses on aspects of compliance with the policy and hence DNAR decision-making, in particular, the nurse's involvement in the decision-making process. The response rate to self-administered questionnaires to practice nurses was 52% (n = 45). Hospital nurses (n = 49) were selected for interview using a quota-sampling technique. Comparisons were made of the views of acute and community staff in their use of the DNAR policy. A clear finding is that hospital nurses wish for more autonomy in DNAR decision-making and improved methods of communicating with medical colleagues when decisions are made. Practice nurses are currently not involved in DNAR decisions. The appropriateness of developing policies for such complex issues as DNAR, when compliance remains low, questions their validity. This study raises awareness, and adds to the discussion for the need for a multidisciplinary approach to DNAR policy.

PMID: 14512860 [PubMed - indexed for MEDLINE]

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

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

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

DESIGN: Qualitative study using semistructured interviews. SETTING: Inpatient and consultation palliative care service of the Royal Victoria Hospital in Montreal, Que.

PARTICIPANTS: Of 113 people interviewed, 13

were patients, 43 were family members, 32 were volunteers, 14 were nurses, and 11 were other staff. METHOD: Interviewers elicited subjects' perspectives on ethical issues. Content analysis was used to identify, code, and categorize themes in the data.

MAIN FINDINGS: Communication difficulties and insufficient resources and staff were the most frequently mentioned problems in this palliative care setting.

CONCLUSION: The findings of this study will help guide policy decisions and setting of educational priorities in end-of-life care, particularly regarding the importance of adequate communication.

PMID: 14708928 [PubMed - indexed for MEDLINE]

20: Can Fam Physician. 2003 Dec;49:1581-5.

Palliative care at home. Dying at home: an increasingly important trend.

[Article in English, French]

Baillargeon L.

Publication Types:

Editorial

PMID: 14708915 [PubMed - indexed for MEDLINE]

21: Can Fam Physician. 2003 Dec;49:1596-7.

A finger or tube in every orifice.

Allen RE.

Publication Types:

Letter

PMID: 14708923 [PubMed - indexed for MEDLINE]

22: Can Fam Physician. 2003 Dec;49:1611-6.

An approach to dyspnea in advanced disease.

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**INTRODUCTION:** To describe an approach to assessment and treatment of dyspnea.  
**SOURCES OF INFORMATION:** New level I evidence can guide management of dyspnea in advanced illness. Assessment and use of adjuvant medications and oxygen relies on level II and III evidence. **MAIN MESSAGE:** Opioids are first-line therapy for managing dyspnea in advanced illness. They are safe and effective in reducing shortness of breath. Neuroleptics are useful adjuvant medications. Evidence does not support use of oxygen for every patient experiencing dyspnea; it should be tried for patients who do not benefit from first-line medications and nonmedicinal therapies. **CONCLUSION:** Opioids relieve dyspnea and are indicated as first-line treatment for dyspnea arising from advanced disease of any cause.

Publication Types:

Review

Review, Tutorial

PMID: 14708926 [PubMed - indexed for MEDLINE]

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

Suicidality in terminally ill Japanese patients with cancer.

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

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**BACKGROUND:** The risk of suicide is higher in patients with cancer than in the general population, making end-of-life care of suicidal terminal patients with cancer critical. To identify factors and longitudinal changes associated with suicidality among terminally ill Japanese patients with cancer, a prospective cohort study was performed. **METHODS:** Consecutive outpatients with cancer who registered with a palliative care unit participated. Structured interviews (e.g., Structured Clinical Interview for DSM-III-R [SCID]) were conducted to assess patient suicidal ideation (Ideation) and interest in requesting euthanasia (Interest) as main outcome measures of suicidality. Possible correlated factors also were investigated. The authors analyzed the data from 140 terminally ill patients with cancer at initial study participation (baseline) whose subsequent survival time was < 6 months. Of these 140 patients, 57 (40.7%) completed the follow-up assessment

after admission to the unit. RESULTS: At baseline, 8.6% of the patients had Ideation and 5.0% had Interest. Self-reported anxiety and depression was significantly associated with Ideation (P= 0.003). Changes in Ideation and Interest occurred in 38.6% and 15.8% of the patients, respectively. Ideation was more likely to change than Interest (P = 0.006). The current study did not identify factors that predict changes and occurrences of suicidal ideation and interest in requesting euthanasia. CONCLUSIONS: Suicidality can change even in terminally ill patients. End-of-life care that focuses on the psychologic distress of dying individuals may be a way of preventing suicide. Copyright 2003 American Cancer Society.

PMID: 14692039 [PubMed - indexed for MEDLINE]

24: Cancer Nurs. 2003 Oct;26(5):392-9.

Assisted dying and end-of-life symptom management.

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This qualitative study aimed to describe symptom management strategies oncology nurses have used in responding to and preventing requests of terminally ill patients with cancer for assisted dying (AD). The study involved secondary analysis of written stories from 36 nurses who agreed to describe their experiences with a request for assisted dying. Of the 36 nurses, 12 refused to support patient requests for AD and described their attempts to control the circumstances of dying by controlling symptoms. The remaining 24 nurses denied ever receiving requests for AD and described symptom management practices believed to prevent such requests. Data were analyzed using Denzin's process of interpretive interactionism. Two themes emerged from the participant's stories: alternative strategies for AD and prevention of requests for AD. The participants shared many examples of clinical interventions and other features of nursing responses to relieve or prevent suffering including physical, emotional, and spiritual care practices; comfort and medication management; and service as teacher-advocate. Both the nurses who had received requests for AD and those who had not used a variety of similar symptom management approaches to alleviate suffering. In doing so, these nurses upheld current standards of both their professional and specialty organizations.

PMID: 14710801 [PubMed - indexed for MEDLINE]

25: Caring. 2003 Nov;22(11):60.

When the end of life is the beginning of something beautiful.

Halamandaris VJ.

PMID: 14658205 [PubMed - indexed for MEDLINE]

26: Caring. 2003 Nov;22(11):20-1.

The role of the psychiatric nurse in a home care palliative care program.

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The psychiatric nurse can play a vital role on a palliative care team. Psychiatric nurses can work with patients to sort out the intense and conflicting feelings that affect patients and their families facing terminal illness and death. Patients can be guided through "life reviews," or nurses can craft interventions to reduce patient anxiety, assist with pain management, or promote physical and psychological comfort.

PMID: 14658199 [PubMed - indexed for MEDLINE]

27: Caring. 2003 Nov;22(11):14-8.

Impacting family satisfaction with hospice care.

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Family satisfaction is one of the most important outcomes for hospice care. A survey conducted in 2001 by Press Ganey Associates found overall high levels of family satisfaction with hospice care, but also highlighted areas needing improvement. Hospices need to pay more attention to ancillary care services, logistical issues, and the problem of late-timed referrals.

PMID: 14658198 [PubMed - indexed for MEDLINE]

28: Caring. 2003 Nov;22(11):6-9.

Palliative care: the legal & regulatory requirements.

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While following the same approach to care as hospice, palliative care reaches patients who do not necessarily have a terminal diagnosis or a life-threatening illness, and/or are seeking curative treatment. Reimbursement methodologies and requirements for palliative care differ from hospice, and are not explicitly covered by federal and state regulations. In the first article of a two-part series, the author

reviews licensing issues, reimbursement requirements, fraud and abuse pitfalls, and cost report requirements for home health agency palliative care programs.

PMID: 14658196 [PubMed - indexed for MEDLINE]

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

Improving care for patients dying in the intensive care unit.

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

Publication Types:

Review

Review, Tutorial

PMID: 14710703 [PubMed - indexed for MEDLINE]

30: Clin J Oncol Nurs. 2003 Nov-Dec;7(6):653-7, 667.

Palliative sedation.

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Concerns about suffering usually arise as patients contemplate end of life. For most, an array of available therapies will alleviate suffering. However, for others, these therapies may not be adequate, despite impeccable assessment and management. In these circumstances, palliative sedation may be an option for the relief of suffering. As patients, families, and clinicians contemplate this option, controversies and concerns about hastening death, euthanasia, and limiting life-sustaining therapies can arise. This article explores some of these concerns.

Publication Types:

Review

Review, Tutorial

PMID: 14705481 [PubMed - indexed for MEDLINE]

31: Clin Med. 2003 Jul-Aug;3(4):342-5.

Clinical approaches to the withdrawal of nutrition and hydration.

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The request for withdrawal of nutrition and hydration from the vegetative patient is rare, but when it occurs it causes considerable anxiety for the clinical team. This anxiety is exacerbated by the need to seek a declaration from court that withdrawal of treatment would be legal. This paper discusses the process from the time of the request to the withdrawal of the tube feeding, and the actions the clinical team needs to take.

Publication Types:

Review

Review, Tutorial

PMID: 12938749 [PubMed - indexed for MEDLINE]

32: Crit Rev Oncol Hematol. 2003 Apr;46(1):17-24.

A clinician's understanding of ethics in palliative care: an American perspective.

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I believe the standard for making ethical decisions should be the same for all patients: appropriate medical interventions, carefully weighing their benefits and burdens, and trying to honor the wishes of the patients. When cure is not possible, the balance between benefits and burdens should shift to greater consideration of the burden side of the equation. The ascendancy of autonomy over other medical ethical principles is the center for most of the ethical dilemmas encountered in palliative care. This paper discusses the issues of autonomy, informed consent, patient capacity, advance directives, futility, "do-not-resuscitate" orders, withholding or withdrawing interventions, euthanasia, and sedation therapy. After 41 years of my personally caring for over 4000 terminally ill patients, primarily at Calvary Hospital, the most practical approach has been to establish trust with patients and families, determining their goals, and diligently applying the principles of beneficence (benefits) and nonmaleficence (burdens) in everyday practice.

Publication Types:

Review

Review, Tutorial

PMID: 12672515 [PubMed - indexed for MEDLINE]

33: Curr Opin Crit Care. 2003 Dec;9(6):545-50.

Communication with family members of patients dying in the intensive care unit.

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In intensive care units the patient is usually unconscious and/or incompetent so that the relationship shifts to the family. Interactions between caregivers and families usually follow one of three models. In the first model, a family representative receives information from the caregivers but does not participate in decisions or physical care. In the second model, the ICU caregivers attempt to provide care consistent with the patient's wishes and values as described by the family. In the third model, the family members communicate their own wishes, provide physical care to the patient, and participate in medical decision-making. After a description of the studies that measured the quality of information provided to ICU families and by discussing the extent to which respecting the principle of patient autonomy is feasible in the ICU, we will review the literature on studies that identified specific needs of families of dying patients and specific challenges faced by intensivists as they seek to inform the families of dying patients. The need for family-centered care and for a better communication within the patient-family-caregiver trio is also highlighted.

Publication Types:

Review

Review, Tutorial

PMID: 14639077 [PubMed - indexed for MEDLINE]

34: Dimens Crit Care Nurs. 2003 Sep-Oct;22(5):223-4.

A personal reflection: "he was a good son".

Rumery LW. lrumery@hotmail.com

PMID: 14508249 [PubMed - indexed for MEDLINE]

35: Dimens Crit Care Nurs. 2003 Sep-Oct;22(5):216-22.

Strategies to improve end-of-life care in the intensive care unit.

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Death is a frequent occurrence in the intensive care unit (ICU). Critical care nurses often feel unprepared to deliver expert end-of-life care. This article proposes specific strategies for critical care nurses to improve the delivery of end-of-life care in the ICU. Critical care nurses can examine beliefs about death; recognize that cure and palliative care coexist; create an environment that supports dying as well as curing; improve communication among providers, patients, and families; provide "small things that make a big difference" at the end-of-life; and locate and utilize support for improving end-of-life care.

Publication Types:

Review

Review, Tutorial

PMID: 14508248 [PubMed - indexed for MEDLINE]

36: 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 - in process]

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

Researching End-of-Life Care: Challenges, Strategies, and Opportunities.

Head B, Ritchie C.

SUMMARY: This article explores the challenges involved in research at the end of life and suggests related strategies and opportunities home care and hospice organizations can use to become involved in end-of-life research.

PMID: 14734994 [PubMed - in process]

38: Hosp Med. 2003 Dec;64(12):752; author reply 752.

Cardiopulmonary resuscitation: junior doctors' attitudes.

de Bono J, Hudsmith L.

Publication Types:

Letter

PMID: 14702794 [PubMed - indexed for MEDLINE]

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

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

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

Publication Types:

Review

Review, Tutorial

PMID: 14708257 [PubMed - indexed for MEDLINE]

40: Issues Law Med. 2003 Fall;19(2):137-43.

Schiavo v. Schiavo. Amicus curiae memorandum of Governor Bush.

Rodriguez RA, Calamas C.

Executive Office of the Governor, Room 209, The Capitol, Tallahassee, Florida  
32399-1050, USA.

Publication Types:

Legal Cases

PMID: 14708258 [PubMed - indexed for MEDLINE]

41: J Adv Nurs. 2003 Dec;44(5):525-33.

Caring for dying people in hospital.

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**BACKGROUND:** Fifty-four per cent of people who die in England and Wales do so in hospital. Evidence suggests that care delivered to dying people in hospital does not match up to the ideal of a good death. These studies have provided organizational and structural explanations of nurses' behaviour that support argument for change at the macro level, in order to improve the quality of care delivered to dying people. There has been little study of the perceptions of nurses working in acute medical settings in relation to their experience of caring for dying people. Therefore, there is little evidence on which to base supportive strategies at the level of individual nurses. **AIM:** In this study we set out to develop an understanding of care for dying people in hospital, from the perspective of newly qualified staff nurses in the UK. The purpose was to build a theory of how nurses might be helped to deliver quality care to dying people in hospital. **METHODS:** This paper is based on an exploratory study underpinned by phenomenological philosophy. In-depth interviews were conducted with 28 newly qualified nurses, focusing on their experiences of caring for dying people on medical wards in two acute hospitals in England in 1999. The interview transcripts were interpreted using a phenomenological approach. **FINDINGS:** The findings presented in this paper relate to commonalities found to underlie study participants' perceptions of their experiences. All the nurses' stories were found to be built around six essences - the personal ideal, the actual, the unknown, the alone, tension and anti-tension. These essences, and the relationships between them, were used to build a model of the experience of caring for dying people in hospital. **LIMITATIONS:** This descriptive study of the experience of individual nurses does not examine the wider social context. It attempts to complement existing sociological theory of death and dying. **CONCLUSION:** The study revealed how a group of newly qualified nurses experienced caring for dying people. We theorize that the model developed has utility as a tool for gaining understanding of the experience of caring for dying people. It is assumed that nurses, through using this model to find explanations for their emotions and behaviours, may gain emotional support that might have a positive impact on the quality of care delivered to dying people in hospital.

PMID: 14651701 [PubMed - indexed for MEDLINE]

42: J Am Geriatr Soc. 2003 Nov;51(11):1595-601.

Quality of life while dying: a qualitative study of terminally ill older men.

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**OBJECTIVES:** To characterize the experience of quality of life while dying from the perspective of terminally ill men. **DESIGN:** Descriptive study involving semistructured interviews. **SETTING:** Patients attending clinics at two university-affiliated medical centers were interviewed in a private conference room or in their homes. **PARTICIPANTS:** Twenty-six men identified by their physicians as having terminal heart disease or cancer. Eligible participants acknowledged that they had serious

illness. MEASUREMENTS: The interview contained open-ended questions such as: "What are the most important things in your life right now?" The interview also contained closed-ended questions about symptom intensity, presence of depressed mood, and other items related to overall quality of life. The open-ended questions were tape-recorded, transcribed, and analyzed using grounded theory methods. The closed-ended questions were analyzed using descriptive statistics. RESULTS: Participants believed that death was near. Participants saw engaging in hobbies and other enjoyable activities as an alternative to moving into the final stage of illness, in which they saw themselves as actively dying. They admitted to occasionally ignoring prescribed diets; these actions improved their overall quality of life but worsened symptoms. New symptoms brought concerns about progression to active dying. They anticipated what their dying would be like and how it would affect others. Participants believed that their actions in the present could improve the quality of their dying and lessen the burden of their deaths on others. Many participants therefore were preparing for death by engaging in such tasks as putting their finances in order and planning their funerals, to relieve anticipated burden on loved ones. CONCLUSION: To help terminally ill patients plan for the end of life, clinicians are encouraged to become familiar with their patients' experiences of living with terminal illness, to identify each patient's unique priorities, and to incorporate that information into care plans aimed at maximizing quality of life at the end of life.

PMID: 14687389 [PubMed - indexed for MEDLINE]

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

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

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

the overall discomfort was low for residents in both facility types. Summary ratings of family satisfaction were significantly higher for the RC/AL (32.1) than the NH (41.2) group ( $P=.016$ ). CONCLUSION: These data suggest that end-of-life care in RC/AL settings appears similar in process and outcomes to that provided in NHs. Thus, aging and dying-in-place can effectively occur in RC/AL.

PMID: 14687388 [PubMed - indexed for MEDLINE]

44: J Cancer Educ. 2003 Summer;18(2):68-72.

Residents from five training programs report improvements in knowledge, attitudes and skills after a rotation with a hospice program.

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BACKGROUND: The faculty of the Center for Palliative Studies teach residents from 5 different primary care residency training programs who rotate at San Diego Hospice: 3 in Internal Medicine, 2 in Family Medicine. Residents participate in the care of patients in the inpatient care setting and make joint home visits with physicians and other team members. A series of 4 lectures on end-of-life care is given on Tuesday mornings: management of pain, other symptoms, interdisciplinary roles of chaplains, social workers, nurses, and grief/bereavement are discussed. In addition, there is a Tuesday noon conference that follows a journal club format. Because of scheduling, residents from some programs are not able to attend all lectures and conferences. METHODS: A 27-item self-assessment evaluation tool was developed for administration to residents before and after their experience. A total of 65 evaluations for residents rotating in academic year 1997-98 and 1998-1999 were collated and analyzed. RESULTS: When evaluated as a whole, residents noted significant improvements in their ability to assess and treat symptoms, to tell patient/family about the dying process and to care for dying patients at home (range in improvement from 26% to 67%,  $p < 0.05$  using paired t-test). About half of the residents perceived that the content was not available elsewhere in their training. CONCLUSION: We conclude that a single hospice rotation can effectively contribute to resident education in multiple programs.

PMID: 12888378 [PubMed - indexed for MEDLINE]

45: J Clin Oncol. 2004 Jan 15;22(2):315-21.

Trends in the aggressiveness of cancer care near the end of life.

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**PURPOSE:** To characterize the aggressiveness of end-of-life cancer treatment for older adults on Medicare, and its relationship to the availability of healthcare resources. **PATIENTS AND METHODS:** We analyzed Medicare claims of 28,777 patients 65 years and older who died within 1 year of a diagnosis of lung, breast, colorectal, or other gastrointestinal cancer between 1993 and 1996 while living in one of 11 US regions monitored by the Surveillance, Epidemiology, and End Results Program. **RESULTS:** Rates of treatment with chemotherapy increased from 27.9% in 1993 to 29.5% in 1996 ( $P = .02$ ). Among those who received chemotherapy, 15.7% were still receiving treatment within 2 weeks of death, increasing from 13.8% in 1993 to 18.5% in 1996 ( $P < .001$ ). From 1993 to 1996, increasing proportions of patients had more than one emergency department visit (7.2% v 9.2%;  $P < .001$ ), hospitalization (7.8% v 9.1%;  $P = .008$ ), or were admitted to an intensive care unit (7.1% v 9.4%;  $P = .009$ ) in the last month of life. Although fewer patients died in acute-care hospitals (32.9% v 29.5%;  $P < .001$ ) and more used hospice services (28.3% v 38.8%;  $P < .001$ ), an increasing proportion of patients who received hospice care initiated this service only within the last 3 days of life (14.3% v 17.0%;  $P = .004$ ). Black patients were more likely than white patients to experience aggressive intervention in nonteaching hospitals but not in teaching hospitals. Greater local availability of hospices was associated with less aggressive treatment near death on multivariate analysis. **CONCLUSION:** The treatment of cancer patients near death is becoming increasingly aggressive over time.

PMID: 14722041 [PubMed - indexed for MEDLINE]

46: J Gen Intern Med. 2003 Sep;18(9):685-95.

Comment in:

J Gen Intern Med. 2003 Sep;18(9):770-1.

The status of medical education in end-of-life care: a national report.

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**OBJECTIVE:** To assess the status of medical education in end-of-life care and identify opportunities for improvement. **DESIGN:** Telephone survey. **SETTING:** U.S. academic medical centers. **PARTICIPANTS:** National probability sample of 1,455 students, 296 residents, and 287 faculty (response rates 62%, 56%, and 41%, respectively) affiliated with a random sample of 62 accredited U.S. medical schools.

**MEASUREMENTS AND MAIN RESULTS:** Measurements assessed attitudes, quantity and quality of education, preparation to provide or teach care, and perceived value of care for dying patients. Ninety percent or more of respondents held positive views about physicians' responsibility and ability to help dying patients. However, fewer than 18% of students and residents received formal end-of-life care education, 39% of students reported being unprepared to address patients' fears, and nearly half felt unprepared to manage their feelings about patients' deaths or help bereaved families. More than 40% of residents felt unprepared to teach end-of-life care. More than 40% of respondents reported that dying patients were not considered good teaching cases, and that meeting psychosocial needs of dying patients was not

considered a core competency. Forty-nine percent of students had told patients about the existence of a life-threatening illness, but only half received feedback from residents or attendings; nearly all residents had talked with patients about wishes for end-of-life care, and 33% received no feedback. CONCLUSIONS: Students and residents in the United States feel unprepared to provide, and faculty and residents unprepared to teach, many key components of good care for the dying. Current educational practices and institutional culture in U.S. medical schools do not support adequate end-of-life care, and attention to both curricular and cultural change are needed to improve end-of-life care education.

PMID: 12950476 [PubMed - indexed for MEDLINE]

47: J Med Philos. 2003 Aug;28(4):461-87.

What is a death with dignity?

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Proponents of the legalization of assisted suicide often appeal to our supposed right to "die with dignity" to defend their case. I examine and assess different notions of "dignity" that are operating in many arguments for the legalization of assisted suicide, and I find them all to be deficient. I then consider an alternative conception of dignity that is based on Aristotle's conception of the conditions on the best life. I conclude that, while such a conception of dignity fits best with our intuitions about the conditions under which a life has dignity, it supports the legalization of assisted suicide only under very limited circumstances.

Publication Types:  
Historical Article

PMID: 14610692 [PubMed - indexed for MEDLINE]

48: J Neurol Neurosurg Psychiatry. 2003 Dec;74 Suppl 4:iv32-iv47.

The management of motor neurone disease.

Leigh PN, Abrahams S, Al-Chalabi A, Ampong MA, Goldstein LH, Johnson J, Lyall R, Moxham J, Mustfa N, Rio A, Shaw C, Willey E; King's MND Care and Research Team.

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Publication Types:  
Review  
Review, Tutorial

PMID: 14645465 [PubMed - indexed for MEDLINE]

49: J Nurs Educ. 2004 Jan;43(1):36-9.

Students' self-identified learning needs: a case study of baccalaureate students designing their own death and dying course curriculum.

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The knowledge needed to provide competent care to dying clients and their families and to meet the established criteria for effective death and dying curricula was explored by junior-level and senior-level baccalaureate honors students, who identified their own learning needs and resources. After completing the self-designed curriculum, student-identified learning needs were compared to the American Association of Colleges of Nursing competencies for providing high-quality end-of-life care. Analysis of the student-identified objectives revealed a high level of congruity with the nationally established competencies.

PMID: 14748533 [PubMed - in process]

50: 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 - in process]

51: J Palliat Care. 2003 Winter;19(4):271-7.

French physicians' attitudes toward legalisation of euthanasia and the ambiguous relationship between euthanasia and palliative care.

Peretti-Watel P, Bendiane MK, Galinier A, Favre R, Lapiana JM, Pegliasco H, Moatti JP.

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In 1999, the French Parliament established a "right to palliative care", which reactivated public debate about euthanasia. In order to investigate jointly physicians' attitude toward palliative care and euthanasia, we conducted a cross-sectional survey of a national sample of French GPs, oncologists, and neurologists. Overall, 917 physicians participated in the survey. Significant proportions of respondents, especially among GPs and neurologists, considered that palliative sedation and withdrawing life-sustaining treatments (WLST) were euthanasia. Multivariate analysis showed that the physicians who had special medical training in palliative care, and those who distinguish palliative sedation and WLST from euthanasia were more likely to oppose legalisation of euthanasia. Thus, French physicians' attitude to the legalisation of euthanasia is strongly influenced by whether or not they distinguish palliative care from euthanasia. Improved palliative care requires better training of the entire medical profession, and clearer guidelines about which end-of-life care practices are legally and ethically acceptable.

PMID: 14959598 [PubMed - in process]

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

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

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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 - in process]

53: J Palliat Med. 2003 Dec;6(6):859-61.

Medical oncology and palliative care: the intersection of end-of-life care.

Weissman D.

PMID: 14740617 [PubMed - in process]

54: J Palliat Med. 2003 Dec;6(6):873-83.

The pursuit of physician-assisted suicide: role of psychiatric factors.

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Physician-assisted suicide (PAS) has attracted considerable professional attention in recent years in the end-of-life care debate. The role of depression and other psychiatric illnesses on the patient's pursuit of PAS is unclear. As part of a qualitative study exploring the motivations, deliberations, and complications experienced by persons with incurable diseases who were actively seeking PAS, we conducted semistructured interviews that were reviewed for psychiatric content. In total, 159 interviews were conducted with 60 participants concerning 12 prospective cases (12 patients and 20 family members) and 23 retrospective cases (28 family members), with more than 3600 pages of transcripts. Depressive symptoms, when present, were not described by the subjects and/or their family members to be an influential factor in their pursuit of PAS; no subject appeared or was described to suffer from depression-related decisional incapacity. Findings from this study, albeit from a small and self-selected sample, highlight not only the importance of avoiding a reductionistic understanding of the role of psychiatric illnesses in contributing to serious pursuit of PAS, but also the pressing need for scientifically rigorous studies of PAS in samples representative of the larger population.

PMID: 14733679 [PubMed - in process]

55: J Palliat Med. 2003 Dec;6(6):1001-12.

The PhoenixCare Program.

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In response to a perceived need for patient access to palliative care and supportive services prior to hospice eligibility, Phoenix-based Hospice of the Valley (HOV) applied for and received a 3-year demonstration grant (1999-2001) from The Robert Wood Johnson (RWJ) Promoting Excellence in End-Of-Life Care Project. HOV established the PhoenixCare project as a demonstration of palliative and coordinated care (case management) services for seriously chronically ill individuals still undergoing active treatment of their disease within a managed care setting. The model emphasized patient/family self-empowerment and prevention. The goal was to demonstrate that it was possible to expand the scope of care for the seriously chronically ill, add palliative care, and improve patient quality of life at less (or no more) cost than that for a comparable group of managed care patients not receiving PhoenixCare services. The model proved most useful to patients willing and able to assume a degree of control over their own care. Physicians referred fewer than 5% of the patients enrolled while managed care plan case managers and hospital discharge planners referred 83%, suggesting that in organized systems of care physicians are not a primary source for patient referrals. The structure and content of the PhoenixCare model, its general acceptability to patients, physicians and managed care plans, and its applicability to other sites are discussed in this article. Outcomes from the study will be published in a subsequent paper.

PMID: 14733694 [PubMed - in process]

56: J Palliat Med. 2003 Dec;6(6):911-8.

Primary care continuity and location of death for those with cancer.

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**BACKGROUND:** Continuity of primary care is known to be associated with both improved processes and outcomes of care. Despite continuity being a desired attribute of end-of-life care and despite the desire by most patients with cancer to die at home, there has been no health services research examining this relationship. **AIM:** To examine the association between family physician continuity of care and the location of death for patients with cancer. **Design of study:** A retrospective population-based study involving secondary data analysis of four linked administrative health databases spanning 6 years of information (1992-1997). **SETTING:** Nova Scotia, Canada **Participants:** All those who died of cancer from 1992 to 1997 and had made at least three ambulatory visits to a family physician. **METHODS:** The relationship of provider continuity of care and an out-of-hospital death was examined using logistic regression. **RESULTS:** Out-of-hospital deaths accounted for 31.6% of the 9714 deaths in the study population. The mean provider continuity of care was 0.78 (standard deviation [SD] 0.22). Those who died out-of-hospital had a greater odds of having received high provider continuity (adjusted odds ratio [OR] = 1.54, 95% confidence interval [CI] = 1.22, 1.93) when compared to those who died in-hospital. There appears to be a modification of this effect by gender with a significant association found for males and not for females. The trends in the point estimates are, however,

similar for both sexes. CONCLUSIONS: This study demonstrates an association between family physician continuity of care and the location of death for those with advanced cancer. Such continuity should be fostered in the development of models of integrated service delivery for end-of-life care.

PMID: 14733683 [PubMed - in process]

57: J S C Med Assoc. 2003 Aug;99(8):224-6.

Comfort always. The Rainey Hospice House: South Carolina's first inpatient hospice.

Woodall HE, Dennis W.

The Rainey Hospice House, South Carolina's first stand-alone inpatient facility opened in September 1998. During the year 2000, 220 inpatients were served in the house. Patients ranged in age from 23 to 107 years old (average age 73). Cancer was the most common hospice diagnosis, followed by congestive heart failure, cardiovascular disease and cerebrovascular disease, dementia, cirrhosis, renal failure, and COPD. Thirty-three percent of patients were in the program less than ten days. Over 98 percent of deaths under hospice care were described as peaceful. During 2000, our outpatients and our inpatients were similar in age, insurance coverage, diagnoses, and time in the program. Inpatient hospice is highly valued by families and patients alike. It is especially useful for the following patients: those with uncontrolled symptoms, those with exhausted care givers, those with no caregivers, those who require total care, and those very close to death. The symptoms most likely to precipitate inpatient admission include pain, nausea, confusion, and agitation. Given the graying of South Carolina's population and the increase in outpatient hospice care, more areas of the state will need inpatient facilities in the future.

PMID: 14508898 [PubMed - indexed for MEDLINE]

58: JAMA. 2004 Jan 28;291(4):483-91.

Supporting family caregivers at the end of life: "they don't know what they don't know".

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Even for patients receiving complex, intensive medical care for serious and life-threatening illness, family caregiving is typically at the core of what sustains patients at the end of life. The amorphous relationship between physicians and the families of patients at the end of life presents both challenges and opportunities for which physicians may be unprepared. Families play important roles in the practical and emotional aspects of patient care and in decision making at the end of life. At the same time, family members may carry significant burdens as a result of their work. Through the perspectives of the wife, daughter, and home care nurse of a patient

who died from pancreatic cancer, we illustrate the range of family caregiver experiences and suggest potentially helpful physician interventions. We describe 5 burdens of family caregiving (time and logistics, physical tasks, financial costs, emotional burdens and mental health risks, and physical health risks) and review the responsibilities of physicians to family caregivers. Based on available evidence, we identify 5 areas of opportunity for physicians to be of service to family members caring for patients at the end of life, including promoting excellent communication with family, encouraging appropriate advance care planning and decision making, supporting home care, demonstrating empathy for family emotions and relationships, and attending to family grief and bereavement. In caring well for family caregivers at the end of life, physicians may not only improve the experiences of patients and family but also find greater sustenance and meaning in their own work.

Publication Types:  
Case Reports

PMID: 14747506 [PubMed - indexed for MEDLINE]

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

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

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

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

were less likely than those cared for in a hospital or by home hospice services to always have been treated with respect at the end of life (68.2% vs 79.6% and 96.2%, respectively). Family members of patients receiving hospice services were more satisfied with overall quality of care: 70.7% rated care as "excellent" compared with less than 50% of those dying in an institutional setting or with home health services ( $P < .001$ ). CONCLUSIONS: Many people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and being treated with respect. Family members of decedents who received care at home with hospice services were more likely to report a favorable dying experience.

PMID: 14709580 [PubMed - indexed for MEDLINE]

60: Linacre Q. 2003 May;70(2):109-20.

Morphine vs. ABT-594: a reexamination by the principle of double effect.

Clark PA.

John McShane Chair in Ethics, Saint Joseph's University, Pittsburgh, PA, USA.

PMID: 14682326 [PubMed - indexed for MEDLINE]

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

End-of-Life Care for Patients with Dementia.

Miller FG, Schulz R, Weiner D, Martire L.

National Institutes of Health, Bethesda, MD 20815, fmiller@nih.gov, University of Pittsburgh, Pittsburgh, PA 15260, schulz@pitt.edu

PMID: 14960754 [PubMed - in process]

62: N J Med. 2003 Nov;100(11):21-2.

Out-of-hospital do-not-resuscitate (DNR) orders. The New Jersey protocol.

Kerwin J, Bauman S.

Overlook Hospital, Summit, New Jersey, USA.

PMID: 14679600 [PubMed - indexed for MEDLINE]

63: Nebr Nurse. 2003 Dec;36(4):29-31; quiz 32.

Continuing education for nurses. Hospice 101.

Meierhenry P.

Publication Types:

Review

Review, Tutorial

PMID: 14705463 [PubMed - indexed for MEDLINE]

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

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

Price CA.

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

PMID: 14730785 [PubMed - in process]

65: Neurology. 2003 Nov 11;61(9):1311-3.

Personal history: a wise owl.

Smith MS. mssq@comcast.net

PMID: 14610155 [PubMed - indexed for MEDLINE]

66: New Sci. 2003 Oct 4-10;180(2415):48-51.

Playing God? Interview by Laura Spinney.

Nitschke P.

Publication Types:  
Interview

PMID: 14686420 [PubMed - indexed for MEDLINE]

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

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

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

Telecommunications Department, Michigan State University, USA.

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

PMID: 14671449 [PubMed - indexed for MEDLINE]

68: Nurs Times. 2003 Nov 25-Dec 1;99(47):20-2.

Dying wishes.

Hemmings P.

PMID: 14689668 [PubMed - indexed for MEDLINE]

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

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

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

PMID: 14624125 [PubMed - indexed for MEDLINE]

70: Nursing. 2003 Sep;33(9):10.

Helping hospice patients.

Johnson J.

Publication Types:  
Letter

PMID: 14562816 [PubMed - indexed for MEDLINE]

71: Orthop Nurs. 2003 Nov-Dec;22(6):446-9.

Caring doesn't end.

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Despite the advances in healthcare technology and the new treatment regimens, all patients are not eligible for these treatments. Although some providers might indicate that there is nothing more that they can do, other healthcare providers do not give up on their patients and families. They continue to provide care, regardless of whether treatment options have been exhausted, and help these patients to have a "good death." The purpose of this article is to use two case examples to show how caring does not end but is rather transformed when intensive treatment ends. There is a discussion of the development of the hospice movement, upholding dignity and respect, and continuing to care. Recommendations for action that inform nursing practice are identified.

Publication Types:  
Case Reports

PMID: 14705475 [PubMed - indexed for MEDLINE]

72: Prof Nurse. 2003 Dec;19(4):213-5.

A model to help nurses caring for patients who are terminally ill.

Murphy M.

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In an age when people are no longer automatically dying from serious illnesses such as cancer or heart disease, patients, families and health-care staff may find coping with a terminal illness difficult. A multidisciplinary team in one hospital used Moos' transitional model, which describes adaptive and coping techniques, in their care of a dying man and his family.

Publication Types:  
Case Reports

PMID: 14692255 [PubMed - indexed for MEDLINE]

73: Psychol Rep. 2003 Dec;93(3 Pt 1):673-4.

Attitudes toward preventing versus assisting suicide: a correction to an earlier publication.

Lester D.

Psychology Program, The Richard Stockton College of New Jersey, Pomona 08240-0195, USA.

A sample of 50 college students was more in favor of preventing suicide than assisting suicide. Support for assisting suicide was associated with judging-perceiving scores on the Keirse-Bates Temperament Survey.

PMID: 14723425 [PubMed - indexed for MEDLINE]

74: Qual Health Res. 2003 Dec;13(10):1353-77.

Balancing: a basic process in end-of-life cancer care.

Thulesius H, Hakansson A, Petersson K.

In this grounded theory study, the authors interviewed caregivers and patients in end-of-life cancer care and found Balancing to be a fundamental process explaining the problem-solving strategies of most participants and offering a comprehensive perspective on both health care in general and end-of-life cancer care in particular. Balancing stages were Weighing--sensing needs and wishes signaled by patients, gauging them against caregiver resources in diagnosing and care planning; Shifting--breaking bad news, changing care places, and treatments; and Compensating--controlling symptoms, educating and team-working, prioritizing and "stretching" time, innovating care methods, improvising, and maintaining the homeostasis of hope. The Balancing outcome is characterized by Compromising, or "Walking a fine line," at best an optimized situation, at worst a deceit.

PMID: 14658351 [PubMed - indexed for MEDLINE]

75: Resuscitation. 2003 Oct;59(1):89-95.

Pre-printed 'do not attempt resuscitation' forms improve documentation?

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OBJECTIVE: Do not-attempt-resuscitate orders are fundamental for allowing patients to die peacefully without inappropriate resuscitation attempts. Once the decision has been made it is imperative to record this information accurately. However, during a related research project we noted that documentation was poor and we thought that the introduction of a pre-printed Do Not Attempt Resuscitation (DNAR) form would improve the documentation process. DESIGN: Two sets of identical research questions were applied retrospectively, 12-months apart, to notes of adult patients (>18 years) who had died during a hospital admission without under-going a resuscitation attempt. Between the first and the second audit, a new resuscitation policy that incorporated a pre-printed DNAR form was introduced into our hospital. RESULTS: A pre-printed DNAR form improved documentation when measured against; clarity of DNAR order (P=0.05), date decision was made/implementation (P=0.014), presence of clinician's signature (P=0.001), identification of the senior clinician making the decision (P< or =0.001) and justification for the DNAR decision (P< or =0.001). However, the pre-printed form made little improvement in encouraging patient involvement in the DNAR decision-making process (P=0.348). CONCLUSION: A pre-printed DNAR form can improve documentation significantly but it has little effect in encouraging patient involvement in the decision-making process.

PMID: 14580738 [PubMed - indexed for MEDLINE]

76: Semin Clin Neuropsychiatry. 2003 Oct;8(4):217-28.

Delirium in the course of cancer treatment.

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Delirium is a frequent complication of cancer treatment and is associated with a high incidence of morbidity and mortality. This article summarizes recent literature on the epidemiology, mechanisms, and treatment of delirium in the patient with cancer. As data continue to emerge on risk factors and pathophysiological mechanisms, recognition of the distinctive features of delirium in specific cancer populations could contribute to a better understanding of consciousness, cognition, perception, and behavior during medical illness.

Publication Types:

Review

Review, Tutorial

PMID: 14613049 [PubMed - indexed for MEDLINE]

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

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

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

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Public and professional discourses in American society about what constitutes a "good death" have flourished in recent decades, as illustrated by the pivotal SUPPORT study and the growing palliative care movement. This paper examines a distinctive medical discourse from high-technology academic medical centers through an analysis of how physicians who are specialists in internal medicine tell stories about the deaths of patients in their care. 163 physicians from two major academic medical centers in the United States completed both qualitative open interviews and quantitative attitudinal measures on a recent death and on the most emotionally powerful death they experienced in the course of their careers. A subsample of 75 physicians is the primary source for the qualitative analysis, utilizing Atlas-ti. "Good death" and "bad death" are common in popular discourse on death and dying. However, these terms are rarely used by physicians in this study when discussing specific patients and individual deaths. Rather, physicians' narratives are nuanced with professional judgments about what constitutes quality end-of-life care. Three major themes emerge from these narratives and frame the positive and negative characteristics of patient death. Time and Process: whether death was expected or unexpected, peaceful, chaotic or prolonged; Medical Care and Treatment Decisions: whether end-of-life care was rational and appropriate, facilitating a "peaceful" or "gentle" death, or futile and overly aggressive, fraught with irrational decisions or adverse events; Communication and Negotiation: whether communication with patients, family and medical teams was effective, leading to satisfying management of end-of-life care, or characterized by misunderstandings and conflict. When these physicians' narratives about patient deaths are compared with the classic sociological observations made by Glaser and Strauss in their study *A Time for Dying* (1968), historical continuities are evident as are striking differences associated with rapid innovation in medical technologies and a new language of medical futility. This project is part of a broader effort in American medicine to understand and improve end-of-life care.

PMID: 14732607 [PubMed - in process]

78: *Spec Care Dentist*. 2003;23(3):84-5.

Should dentists be included as members of the hospice care team?

Wilwert M.

Publication Types:  
Editorial

PMID: 14650555 [PubMed - indexed for MEDLINE]

79: *Suicide Life Threat Behav*. 2003 Summer;33(2):192-200.

The Werther effect and assisted suicide.

Frei A, Schenker T, Finzen A, Dittmann V, Kraeuchi K, Hoffmann-Richter U.

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In the course of a large epidemiological study in the region of Basle, Switzerland, from 1992 to 1996, a considerable rise in suicides assisted by the right-to-die society EXIT was uncovered after wide press coverage of an assisted double suicide of a prominent couple in that region in March 1995. Further investigation revealed that the rise of assisted suicides for a period of 2 years after the critical event was statistically significant compared to the 2 years previous to the double suicide. This was especially true for women older than 65 years. Hence, the almost enthusiastic kind of reporting about this event was apt to induce imitation suicides or a "Werther-effect."

PMID: 12882420 [PubMed - indexed for MEDLINE]