



End of Life Care November 2003

1: Adv Nurse Pract. 2003 Sep;11(9):65-8, 72.

Terminal dementia in the elderly. Awareness leads to more appropriate care.

Byrd L.

Publication Types:

Review

Review, Tutorial

PMID: 14521110 [PubMed - indexed for MEDLINE]

2: Am J Geriatr Psychiatry. 2003 Jul-Aug;11(4):393-405.

Hope and hopelessness at the end of life.

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Efforts to improve end-of-life care have been hindered by widespread delays in discussing and initiating this care. The dynamics of hope and hopelessness may be crucial in these delays. The author reviews recent literature concerning hope and hopelessness at the end of life. Modern dying is more prolonged and more shaped by human choice than ever before. Therefore, hope and hopelessness play a more active role in the dying process. Hopelessness is not a simple product of prognosis, but is shaped by state and trait psychological factors. Hope at the end of life can come in various forms: for cure, for survival, for comfort, for dignity, for intimacy, or for salvation. Hopelessness at the end of life is therefore not simply the absence of hope, but attachment to a form of hope that is lost. The concept of anticipatory grief may help us interpret hope and hopelessness at the end of life. Improving end-of-life care will require looking beyond prognosis and preferences to understand the dynamics of hope and hopelessness. To be successful at diversifying hope at the end of life, we must foster the trusting interpersonal environment where this is possible.

Publication Types:

Review

Review, Academic

PMID: 12837668 [PubMed - indexed for MEDLINE]

3: Ann Intern Med. 2003 Nov 4;139(9):740-7.

The quality of medical care provided to vulnerable community-dwelling older patients.

Wenger NS, Solomon DH, Roth CP, MacLean CH, Saliba D, Kamberg CJ, Rubenstein LZ, Young RT, Sloss EM, Louie R, Adams J, Chang JT, Venus PJ, Schnelle JF, Shekelle PG.

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BACKGROUND: Many people 65 years of age and older are at risk for functional decline and death. However, the resource-intensive medical care provided to this group has received little evaluation. Previous studies have focused on general medical conditions aimed at prolonging life, not on geriatric issues important for quality of life. **OBJECTIVE:** To measure the quality of medical care provided to vulnerable elders by evaluating the process of care using Assessing Care of Vulnerable Elders quality indicators (QIs). **DESIGN:** Observational cohort study. **SETTING:** Managed care organizations in the northeastern and southwestern United States. **PATIENTS:** Vulnerable older patients identified by a brief interview from a random sample of community-dwelling adults 65 years of age or older who were enrolled in 2 managed care organizations and received care between July 1998 and July 1999. **MEASUREMENTS:** Percentage of 207 QIs passed, overall and for 22 target conditions; by domain of care (prevention, diagnosis, treatment, and follow-up); and by general medical condition (for example, diabetes and heart failure) or geriatric condition (for example, falls and incontinence). **RESULTS:** Patients were eligible for 10 711 QIs, of which 55% were passed. There was no overall difference between managed care organizations. Wide variation in adherence was found among conditions, ranging from 9% for end-of-life care to 82% for stroke care. More treatment QIs were completed (81%) compared with other domains (follow-up, 63%; diagnosis, 46%; and prevention, 43%). Adherence to QIs was lower for geriatric conditions than for general medical conditions (31% vs. 52%; $P < 0.001$). **CONCLUSIONS:** Care for vulnerable elders falls short of acceptable levels for a wide variety of conditions. Care for geriatric conditions is much less optimal than care for general medical conditions.

PMID: 14597458 [PubMed - in process]

4: Ann Intern Med. 2003 Oct 21;139(8):705; author reply 705.

Comment on:

Ann Intern Med. 2003 Jan 7;138(1):65-8.

CPR for patients labeled DNR.

Karnath BM.

Publication Types:

Comment

Letter

PMID: 14568869 [PubMed - indexed for MEDLINE]

5: Ann Intern Med. 2003 Oct 21;139(8):704; author reply 705.

Comment on:

Ann Intern Med. 2003 Jan 7;138(1):65-8.

CPR for patients labeled DNR.

LeGrand SB.

Publication Types:

Comment

Letter

PMID: 14568868 [PubMed - indexed for MEDLINE]

6: Ann Intern Med. 2003 Oct 21;139(8):704; author reply 705.

Comment on:

Ann Intern Med. 2003 Jan 7;138(1):65-8.

CPR for patients labeled DNR.

Freer JP.

Publication Types:

Comment

Letter

PMID: 14568867 [PubMed - indexed for MEDLINE]

7: Ann Intern Med. 2003 Oct 21;139(8):704; author reply 705.

Comment on:

Ann Intern Med. 2003 Jan 7;138(1):65-8.

CPR for patients labeled DNR.

Gillick M.

Publication Types:

Comment

Letter

PMID: 14568866 [PubMed - indexed for MEDLINE]

8: Ann R Coll Physicians Surg Can. 2002 Mar;35(2):107-8.

Quality end-of-life care: the rights of every Canadian.

Reichenfeld HF.

hasreich@systemweb.com

PMID: 12755131 [PubMed - indexed for MEDLINE]

9: Bioethics. 2003 Jun;17(3):261-78.

Comment in:

Bioethics. 2003 Jun;17(3):279-89.

Comment on:

Bioethics. 2000 Apr;14(2):120-33.

Anorexia nervosa and refusal of naso-gastric treatment: a response to Heather Draper.

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Imposing artificial feeding on people with anorexia nervosa may be unethical. This seems to be Heather Draper's suggestion in her article, 'Anorexia Nervosa and Respecting a Refusal of Life-Prolonging Therapy: A Limited Justification.' Although this is an important point, I shall show that the arguments supporting this point are flawed. Draper should have made a brave claim: she should have claimed that people with anorexia nervosa, who competently decide not to be artificially fed, should be respected because everybody is entitled to exercise their autonomy, not only 'in the middle' of their life, but also at the end of it, or when their own life is at stake, because autonomy also extends to the most difficult moments of our life, and, ultimately, 'stretches [...] far out into the distance' at the end of it. I explain why Draper should have made the brave claim, and why she has not made it. I conclude that a defence of people's entitlement to competently refuse artificial feeding cannot rest upon the arguments developed by Draper. Whether or not we should respect competent refusal of artificial feeding depends on the normative strength that we are ready to ascribe to the principle of autonomy, to the moral relevance that we ascribe to the circumstances in which a person's autonomy is exercised, and, perhaps, eventually, on our sense of compassion.

Publication Types:

Comment

PMID: 14533609 [PubMed - indexed for MEDLINE]

10: BMJ. 2003 Oct 11;327(7419):832.

Nazi's euthanasia files are made public.

Tuffs A.

Publication Types:
News

PMID: 14560717 [PubMed - indexed for MEDLINE]

11: BMJ. 2003 Oct 11;327(7419):830.

German doctor is investigated for killing 76 patients with morphine.

Tuffs A.

Publication Types:
News

PMID: 14551077 [PubMed - indexed for MEDLINE]

12: Camb Q Healthc Ethics. 2003 Summer;12(3):322-5.

Hospice with a Zen twist: a talk with Zen hospice founder Frank Ostaseski.
Interview by Steve Heilig.

Ostaseski F.

Publication Types:
Interview

PMID: 12889339 [PubMed - indexed for MEDLINE]

13: Camb Q Healthc Ethics. 2003 Summer;12(3):310-21.

Oregon v. Ashcroft: the battle over the soul of medicine.

Rich BA.

Bioethics Program, University of California, Davis Medical Center, Sacramento,
USA.

Publication Types:

Legal Cases

PMID: 12889338 [PubMed - indexed for MEDLINE]

14: Crit Care. 2003 Oct;7(5):339-41. Epub 2003 Sep 02.

Recently published papers: curing, caring and follow-up.

Williams G.

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Publication Types:

Review

Review, Tutorial

PMID: 12974962 [PubMed - indexed for MEDLINE]

15: Crit Care Clin. 2003 Oct;19(4):789-810, viii.

End-of-life care in the critically ill geriatric population.

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As the geriatric population in the United States increases and better management of chronic diseases improves survival, more elderly will become critically ill and potentially require treatment in an intensive care unit (ICU). Dan Callahan has written, "... we will live longer lives, be better sustained by medical care, in return for which our deaths in old age are more likely to be drawn out and wild." Although no health care provider hopes for a drawn out and wild death for elderly patients, many geriatric persons will succumb to disease and die after having chosen and received ICU care. Recent data suggest that, on average, 11% of Medicare recipients spend more than 7 days in the ICU within 6 months before death.

PMID: 14601720 [PubMed - in process]

16: Crit Care Nurs Clin North Am. 2003 Sep;15(3):355-62.

Using complementary and alternative therapies to promote comfort at end of life.

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Dying is a journey for all involved. We have been fortunate to work in a hospital with both an ICU and a palliative care/hospice unit. We have transferred patients for whom care was withdrawn and who were still alive on the next day to the palliative care unit and have found the transfer to work to maximize comfort in dying. For many patients and families who have developed relationships with the staff in their ICU, the combination of established relationships, traditional therapies, and CAT maximizes the comfort during the dying process.

PMID: 12943142 [PubMed - indexed for MEDLINE]

17: Crit Care Nurse. 2003 Aug;23(4):8, 10.

At the juncture of life and death, it matters that you are there.

Alspach G.

Publication Types:
Editorial

PMID: 12961778 [PubMed - indexed for MEDLINE]

18: Eur J Cancer Care (Engl). 2003 Sep;12(3):212-4.

End-of-life decision making--have we got it right?

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There are wide-spread misconceptions about palliative care. Various treatments used in palliative care have a potential to shorten, and at times even prolong life. However, such treatments are used with a view to enhance quality of life and/or death. Withholding and withdrawal of life-prolonging treatments are not equivalent to assisting death. It is important that patients who are approaching death are sensitively encouraged to make informed choices about such treatments. At the same time, there is no obligation on part of a health professional to provide a futile treatment. This personal view of two palliative care physicians aims to explore some of the difficulties surrounding end-of-life care.

PMID: 12919299 [PubMed - indexed for MEDLINE]

19: Geriatr Nurs. 2003 Jul-Aug;24(4):202-5.

A couple's last journey.

Usmiani R.

Mount Saint Vincent University, Halifax, Nova Scotia, Canada.

PMID: 14560289 [PubMed - indexed for MEDLINE]

20: Health News. 2003 Sep;9(9):7-8.

Hospice nurses: patients who refuse food and water die peacefully.

[No authors listed]

Publication Types:
News

PMID: 14584473 [PubMed - indexed for MEDLINE]

21: Health Soc Work. 1999 Feb;24(1):57-64.

Preparation for oncology settings: what hospice social workers say they need.

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According to recent data, 78 percent of hospice social workers' direct practice hours are spent with patients and families diagnosed with terminal cancer. A national sample of 108 hospice social workers participated in an exploratory study investigating the influence of their formal academic training, informal on-the-job training, and related professional and personal experiences on their preparation for oncology social work. Findings suggest that social workers view both the generalist or core courses as well as the specialist and elective courses as important in preparing them for oncology social work. In addition, on-the-job training focusing on medical terminology, interdisciplinary, collaboration, death and dying and the integration of personal experiences are important for continuing growth and success in this work. Implications for social work practice, research, and formal and informal educational opportunities are discussed.

PMID: 14533420 [PubMed - indexed for MEDLINE]

22: Hematol Oncol Clin North Am. 2002 Dec;16(6):1381-96.

Advance directives and life-sustaining treatment: a legal primer.

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Advanced directives are a natural extension of a patient's right to self-determination of what actions will be taken upon his or her body. As such, instructional advanced directives such as living wills and DNR orders represent important patient preferences that must be adhered to in the health care context. In addition, health care proxies provide the patient with an authority for decision making in the event of incapacity. Overall, advanced directives provide health care providers, patients, and patient families with control over the kinds of care they do and do not desire at the end of life. Understanding the legal status of these instruments will provide the physician with another tool to advocate effectively for the patient.

Publication Types:

Review
Review, Tutorial

PMID: 12512173 [PubMed - indexed for MEDLINE]

23: Int J Palliat Nurs. 2003 Aug;9(8):360-1; author reply 361.

Comment on:

Int J Palliat Nurs. 2003 Apr;9(4):157-65.

Staff views on cardiopulmonary resuscitation.

Thorns A.

Publication Types:

Comment
Letter

PMID: 12971374 [PubMed - indexed for MEDLINE]

24: Int J Palliat Nurs. 2003 Aug;9(8):326-35.

Hospice at home 2: evaluating a crisis intervention service.

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This article presents an evaluation of a rapid-response crisis-intervention service, hospice at home (H@H), for patients with advanced cancer. The project took place in Glasgow, UK, between July 1999 and May 2001. An integral part of the (H@H) project was the concurrent evaluation, which attempted to explore a range of service and user outcomes. The service was able to prevent admission to, or facilitate discharge from, institutional care on 62 occasions. The evaluation found significant improvements in some areas of pain and symptom management. High levels of satisfaction were recorded by all service users. A partial cost analysis revealed that the medical and nursing support costs for the (H@H) would have been substantially reduced if throughput had been higher.

The (H@H) project team agreed that a valuable lesson learned from the project was the importance of involving all key players from the outset when determining the requirements of a new service initiative.

PMID: 12968118 [PubMed - indexed for MEDLINE]

25: Int J Palliat Nurs. 2003 Jul;9(7):298-307; discussion 307.

Evaluating the Navigate Care Model: clinical palliative care pathways based on anticipated care outcomes.

Nightingale E, Kristjanson LJ, Toye C.

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The Navigate Care Model (NCM) specifies clinical pathway assignments for hospice patients based on the anticipated outcomes of death, discharge home, or discharge into residential care. This study, set in a freestanding, inpatient hospice, evaluated the effects of NCM implementation on 338 patients, 154 family members and the organization, including 49 staff. Accuracy of pathway assignment on admission was also assessed. The results indicate that patients' symptoms were managed as well or better than previously, as compared with 1998 data. Discharged patients reported being highly satisfied with care and there were fewer readmissions. Families reported greater satisfaction with care than those surveyed previously, as compared with 1999 data. Staff reported initial negative effects but elected to retain a refined version of the model after the study. Pathway assignments on admission were correct 64% of the time, 92% correct when assignment was for terminal care. Clinical pathways based upon the expected outcomes of death or discharge appear to offer benefits for patients and families.

PMID: 12920450 [PubMed - indexed for MEDLINE]

26: Int J Palliat Nurs. 2003 Jul;9(7):283-9.

Professionals' perceptions of maintaining personhood in hospice care.

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This qualitative study examines the attempts made by hospice staff to support and maintain the personhood of hospice patients. The study was conducted over a six-month period at two hospice facilities in northwest England. Thirty staff members were interviewed about their interpretation of the hospice philosophy and how this influences their work with regard to patient personhood. Staff employed methods of normalizing the often-distressing symptoms that accompany serious illness, with the aim of maintaining personhood and dignity. Related to the support of personhood, is the concept of the "special" patient. Staff members discussed feelings of attachment towards particular patients that had

developed out of the care-giving relationship. There was no suggestion that staff perceived special patients as receiving preferential treatment at the expense of other patients. However, experiences with "special" patients positively impacted staff members by reinforcing occupational choice and the inherent rewards of the profession.

PMID: 12920448 [PubMed - indexed for MEDLINE]

27: Intensive Crit Care Nurs. 2003 Aug;19(4):241-51.

End-of-life decisions in Swedish ICUs. How do physicians from the admitting department reason?

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OBJECTIVE: To study how physicians from the admitting department reason during the decision-making process to forego life-sustaining treatment of patients in intensive care units (ICUs). DESIGN: Qualitative interview that applies a phenomenological approach. SETTING: Two ICUs at one secondary and one tertiary referral hospital in Sweden. PARTICIPANTS: Seventeen admitting-department physicians who have participated in decisions to forego life-sustaining treatment. RESULTS: The decision-making process as it appeared from the physicians' experiences was complex, and different approaches to the process were observed. A pattern of five phases in the process emerged in the interviews. The physicians described the process principally as a medical one, with few ethical reflections. Decision-making was mostly done in collaboration with other physicians. Patients, family and nurses did not seem to play a significant role in the process. CONCLUSION: This study describes how physicians reasoned when confronted with real patient situations in which decisions to forego life-sustaining treatment were mainly based on medical--not ethical--considerations.

PMID: 12915113 [PubMed - indexed for MEDLINE]

28: J Am Coll Surg. 2003 Oct;197(4):661-86.

Office of Promoting Excellence in End-of-Life Care: Surgeon's Palliative Care Workgroup report from the field.

Surgeons Palliative Care Workgroup.

PMID: 14562800 [PubMed - indexed for MEDLINE]

29: J Gerontol Nurs. 2003 Sep;29(9):4-14.

The history of advance directives. A literature review.

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Publication Types:
Historical Article
Review
Review, Tutorial

PMID: 14528744 [PubMed - indexed for MEDLINE]

30: J Law Med. 2003 Aug;11(1):77-92.

Private thoughts of public representatives: assisted death, voluntary euthanasia and politicians.

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Assisted death and voluntary euthanasia have received significant and sustained media attention in recent years. High-profile cases of people seeking assistance to end their lives have raised, at least in the popular press, debate about whether individuals should be able to seek such assistance at a time when they consider their suffering to be unbearable or their quality of life unsatisfactory. Other recent developments include a number of attempts to legislate on the issue by the minor parties in Australia and the successful enactment of legislation in a few overseas jurisdictions. However, despite all of the recent attention that has focused on assisted death and voluntary euthanasia, a discussion of the adequacy of existing laws has not made it onto the political agenda of any of the Australian State or Territory governments. This is in spite of the fact that the private views of the majority of our elected Members of Parliament may be supportive of reform. This article explores the role of politicians' views and, as a case study, considers the opinions expressed by a number of Queensland Members of Parliament. In light of the views of these politicians and those of members of the public, as well as considerations arising from current medical practice, the article argues that there is a need for open political debate on assisted death and voluntary euthanasia. The article also suggests ways that such a debate may be achieved while minimising any political impact on governments that are prepared at least to consider this issue.

PMID: 14526728 [PubMed - indexed for MEDLINE]

31: J Law Med. 2003 Aug;11(1):59-76.

The law and practice associated with advance directives in Canada and Australia: similarities, differences and debates.

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This article is a summary of research that investigated the Canadian and Australian legislative framework associated with advance directives in health care. The research focused on the context in which older people are encouraged to use advance directives. These are directions about refusal of medical treatment given in advance of incompetence. An advance directive may be given in a written document (living will) expressing one's wishes, by appointing another person (proxy) to make the decisions, or as a combination of the two. A lack of consistency and clarity about the terminology was found in both countries. This could be a barrier for older people to express their wishes in advance. Several confusing issues were also identified with the legislation related to advance directives. There appears to be a move towards appointing a substitute decision-maker, but with significant differences across the Australian States and in Canadian Provinces. The "conversation" about future decisions emerged as an important theme, together with an emphasis on the process of "advance care planning" replacing the focus on advance directive forms.

Publication Types:

Legal Cases

Review

Review, Tutorial

PMID: 14526727 [PubMed - indexed for MEDLINE]

32: J Music Ther. 2003 Summer;40(2):113-37.

The effects of music therapy on the quality and length of life of people diagnosed with terminal cancer.

Hilliard RE.

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The purpose of this study was to evaluate the effects of music therapy on quality of life, length of life in care, physical status, and relationship of death occurrence to the final music therapy interventions of hospice patients diagnosed with terminal cancer. Subjects were adults who were living in their homes, receiving hospice care, and were diagnosed with terminal cancer. A total of 80 subjects participated in the study and were randomly assigned to one of two groups: experimental (routine hospice services and clinical music therapy) and control (routine hospice services only). Groups were matched on the basis of gender and age. Quality of life was measured by the Hospice Quality of Life Index-Revised (HQOLI-R), a self-report measure given every visit. Functional status of the subjects was assessed by the hospice nurse during every visit using the Palliative Performance Scale. All subjects received at least two visits and quality of life and physical status assessments. A repeated measures ANOVA revealed a significant difference between groups on self-report quality of life scores for visits one and two. Quality of life was higher for those subjects receiving music therapy, and their quality of life increased over time

as they received more music therapy sessions. Subjects in the control group, however, experienced a lower quality of life than those in the experimental group, and without music, their quality of life decreased over time. There were no significant differences in results by age or gender of subjects in either condition. Furthermore, there were no significant differences between groups on physical functioning, length of life, or time of death in relation to the last scheduled visit by the music therapist or counselor. This study provides an overview of hospice/palliative care, explains the role of music therapy in providing care, and establishes clinical guidelines grounded in research for the use of music therapy in improving the quality of life among the terminally ill.

Publication Types:

Clinical Trial

Randomized Controlled Trial

PMID: 14505443 [PubMed - indexed for MEDLINE]

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

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

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

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While much attention has been directed at improving the quality of care at the end of life, few studies have examined what determines a good death in different individuals. We sought to identify common domains that characterize a good death in a diverse range of community-dwelling individuals, and to describe differences that might exist between minority and non-minority community-dwelling individuals' views. Using data from 13 focus groups, we identified 10 domains that characterize the quality of the death experience: 1) physical comfort, 2) burdens on family, 3) location and environment, 4) presence of others, 5) concerns regarding prolongation of life, 6) communication, 7) completion and emotional health, 8) spiritual care, 9) cultural concerns, 10) individualization. Differences in minority compared to non-minority views were apparent within the domains of spiritual concerns, cultural concerns, and individualization. The findings may help in efforts to encourage more culturally sensitive and humane end-of-life care for both minority and non-minority individuals.

PMID: 14606328 [PubMed - in process]

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

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

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Institute of Palliative Care, Ontario, Canada.

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

PMID: 14606329 [PubMed - in process]

35: J Palliat Care. 2003 Summer;19(2):77-86.

No time for dying: a study of the care of dying patients in two acute care Australian hospitals.

Pincombe J, Brown M, McCutcheon H.

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OBJECTIVES: Research was conducted in two teaching hospitals in Australia to collect data on the care of patients dying in the acute care setting.
METHODOLOGY: Non-participant observation of the care of dying patients in medical wards was the primary method of data collection and selected staff were interviewed. Observers collected data on the type of care, who gave the care, and the time given to care. Thematic analysis was applied to both the observational and interview data. **PARTICIPANTS:** Patients selected were over the age of 18 years, with a terminal diagnosis and an estimated six days to live. **RESULTS:** Three major factors emerged from the data to form the context in which patients were cared for and died: 1) the organizational factor, 2) the environmental factor, and 3) the human factor. The presence or absence of family members influenced the amount of care given. If family members were not present, dying could be an isolating experience, with minimal care focused on routine hospital activities. **CONCLUSION:** This research indicated that the principles of palliative care are yet to be incorporated in the acute care hospital setting.

PMID: 12955923 [PubMed - indexed for MEDLINE]

36: J Palliat Care. 2003 Summer;19(2):100-6.

Legitimizing do-not-resuscitate orders: a discursive study of cancer patients'

speech.

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This article examines how patients with cancer construct and legitimate do-not-resuscitate (DNR) orders. Semi-structured interviews with 23 outpatients attending an oncology clinic were tape-recorded, transcribed, and analyzed in accordance with discourse-analytic methodology. Results indicate some variability for participants regarding the meaning of DNR orders, which were nonetheless viewed as appropriate and desirable. The patient's subsequent death was legitimated primarily through the invocation of highly valorized discourses within Western society: nature, autonomy, and compassion. Non-compliance with DNR orders, or the instigation of CPR was seen as violating nature, infringing autonomy, and as uncompassionate. The combined effect was to construct dying as a natural event which is the concern of the individual patient and their family, endorsing medical non-intervention in the process. This research provides support, from the patients' viewpoint, for a policy of non-intervention when death is imminent and inevitable, and for those questioning the wisdom of a default policy of initiating CPR on any hospitalized patient, especially those patients inevitably in the process of dying.

PMID: 12955926 [PubMed - indexed for MEDLINE]

37: J Palliat Med. 2003 Jun;6(3):391-9.

Palliative care education: an intervention to improve medical residents' knowledge and attitudes.

Fischer SM, Gozansky WS, Kutner JS, Chomiak A, Kramer A.

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BACKGROUND: Medical care at the end of life remains poor. One approach to improving end-of-life care is through education of medical trainees. However, evidence regarding the structure of an ideal educational intervention is sparse. **OBJECTIVE:** To test an innovative curriculum designed to improve medical resident knowledge and decrease anxiety surrounding end-of-life care. **METHODS:** Quasiexperimental study of medical trainees in a large academic internal medicine residency. Attitudes and knowledge were measured at baseline and at completion of a 1-month clinical ward rotation for both control (n = 40) and intervention groups (n = 30) using the Collett-Lester Death Anxiety Scale (C-LDAS), the Semantic Differential Scale (SDS), and a 16-question knowledge-based test. Residents in the intervention group completed four 1-hour sessions focused on end-of-life issues. **RESULTS:** Baseline anxiety levels were high while knowledge scores were poor. Linear regression modeling demonstrated that pretest scores were the strongest predictor of post-test scores for all three measures. Additional significant predictors for the knowledge test were prior palliative care experience and year of training (p = 0.02), while prior palliative care experience alone contributed to the SDS model (p = 0.06). No

significant improvements on the SDS, C-LDAS, or knowledge test occurred after the curriculum intervention. CONCLUSIONS: Our classroom intervention had no significant effect on residents' attitudes towards or knowledge of end-of-life care. The fact that prior palliative care experience affects baseline scores provides a strong argument for continued research for an effective curriculum for end-of-life education, perhaps focusing on clinical rather than didactic experiences in palliative care.

PMID: 14509484 [PubMed - indexed for MEDLINE]

38: J Palliat Med. 2003 Jun;6(3):409-15.

Comment in:

J Palliat Med. 2003 Jun;6(3):429-31.

Responding to requests regarding prayer and religious ceremonies by patients near the end of life and their families.

Lo B, Kates LW, Ruston D, Arnold RM, Cohen CB, Puchalski CM, Pantilat SZ, Rabow MW, Schreiber RS, Tulskey JA.

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Prayer and religious ceremonies may help patients near the end of life and their relatives find comfort and discover meaning in their lives. In this paper, we analyze how physicians might respond in two situations regarding prayer and religious ceremonies. First, how should physicians respond when such patients or their families ask physicians to pray for them or with them? Physicians' responses to such requests will depend on their own religious and spiritual beliefs, the congruence of their beliefs with those of the patient and family, and their relationship with the patient. Many physicians may be willing to be present and stand silently while the patient prays. Second, how should physicians respond when such patients and families seek to carry out their religious and spiritual practices in the hospital? Religious ceremonies can provide meaning, hope, and solace to patients and families. Institutional guidelines regarding religious ceremonies should allow as much leeway as is compatible with good care both for the patient for whom the ritual is offered and also for other patients within the facility. Physicians should inquire whether there are religious and spiritual practices that patients and families would like to engage in. However, physicians should be cautious about recommending specific ceremonies or practices. Physicians can respond to requests and respect patients' spiritual needs in ways that may deepen the therapeutic doctor-patient relationship, without compromising their own religious and spiritual beliefs or professional roles.

PMID: 14509486 [PubMed - indexed for MEDLINE]

39: J Palliat Med. 2003 Jun;6(3):429-31.

Comment on:

J Palliat Med. 2003 Jun;6(3):409-15.

Spirituality and medicine.

Sheehan MN.

Publication Types:

Comment

Editorial

PMID: 14509489 [PubMed - indexed for MEDLINE]

40: J Palliat Med. 2003 Jun;6(3):381-90.

Oregon physicians' perceptions of patients who request assisted suicide and their families.

Ganzini L, Dobscha SK, Heintz RT, Press N.

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In 1997, the Oregon Death with Dignity Act was enacted, allowing a physician to prescribe a lethal dose of medication for a competent, terminally ill patient who requests one. In 2000, we conducted single, semistructured, in-depth, face-to-face interviews with 35 Oregon physicians who received a request for a lethal prescription. The interviews focused on physicians' perceptions of patients who requested assisted suicide, the reasons for the request, and the reactions of their families. The interviews were audiotaped, transcribed, and analyzed using qualitative techniques. Physicians described requesting patients as having strong and vivid personalities characterized by determination and inflexibility. These individuals wanted to control the timing and manner of death and to avoid dependence on others. These preferences reflected long-standing coping and personality traits. Physicians perceived that these patients viewed living as purposeless and too effortful, and that they were ready for death. The requests, which were forceful and persistent, could occur at any point after diagnosis of the terminal illness, and were paralleled by refusal of medical interventions including palliative treatments. Many family members were reluctant to support these requests until they recognized the strength of the preference.

PMID: 14509483 [PubMed - indexed for MEDLINE]

41: J Palliat Med. 2003 Jun;6(3):345-50.

Comment in:

J Palliat Med. 2003 Jun;6(3):425-7.

Development of a clinical practice guideline for palliative sedation.

Braun TC, Hagen NA, Clark T.

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Palliative sedation is an effective symptom control strategy for patients who suffer from intractable symptoms at the end of life. Evidence suggests that the use of this practice varies considerably. In order to minimize variation in the practice of palliative sedation within our health region, we developed a clinical practice guideline (CPG) for the use of palliative sedation. Using available evidence from the literature, a five step process was employed to develop the CPG: (1) a working group was charged with the mandate to develop a draft guideline; (2) a working definition for palliative sedation was developed; (3) criteria for use of sedation were determined; (4) critical steps to be taken prior to initiation of sedation were defined; and (5) the CPG was reviewed by local stakeholders. Feedback from the wider group of stakeholders was used to arrive at the final CPG, which subsequently received approval from the local Medical Advisory Board. The process used to develop the CPG served to develop consensus within the local community of palliative care clinicians regarding the practice of palliative sedation. Subsequently, the CPG was used as a tool for educating other health care providers.

PMID: 14509479 [PubMed - indexed for MEDLINE]

42: J Palliat Med. 2003 Jun;6(3):337-8.

Why hospice needs palliative medicine and vice versa.

McGrew DM; AAHPM.

Publication Types:
News

PMID: 14509476 [PubMed - indexed for MEDLINE]

43: J Palliat Med. 2003 Jun;6(3):511-9.

Enhancing communication for end-of-life care: an electronic advance directive process.

Bricker LJ, Lambing A, Markey C.

Henry Ford Health System, Division of Hematology/Oncology, Detroit, Michigan 48202, USA. lbricke1@hfhs.org

An advance directive, a description of one's future preferences for medical treatment, must be easily available to care providers to ensure that one's treatment preferences are honored. The transition of our health care system to an electronic medical record complicated the availability of a patient's written advance directive. This paper describes the development of an electronic advance directive to facilitate access to a patient's treatment wishes at any site in our health care system. The successes and challenges encountered in the

development process are discussed.

PMID: 14509500 [PubMed - indexed for MEDLINE]

44: J Palliat Med. 2003 Jun;6(3):501-10.

Establishing a culturally sensitive palliative care program in rural Alaska Native American communities.

DeCourtney CA, Jones K, Merriman MP, Heavener N, Branch PK.

Helping Hands Program, Bristol Bay Area Health Corporation, Dillingham, Alaska, USA. cadecourtney@yahoo.com

End-of-life programs that provide an option for patients to die at home are available in most U.S. communities. However, Alaska Natives living in remote Alaska villages often die alone in hospitals and nursing homes hundreds of miles away from home. The Bristol Bay Area Health Corporation (BBAHC), a tribal organization, is the sole provider of comprehensive primary care services to 34 Alaska Native villages located within a 46,000 square mile area in southwest Alaska. The closest tertiary care hospital is 329 air miles away in Anchorage. Because of the high cost of, and difficulties encountered in trying to deliver end-of-life care services to remote communities, a village-focused, culturally sensitive, volunteer and primary care program combined with a regionally based physician and home health nurse to deliver multi-disciplinary palliative care was developed. The Helping Hands Program blends cultural practices with contemporary palliative care medicine to allow Alaska Natives and others living in remote communities to be cared for at home through the end of life. Since the program was implemented in 1999, the percentage of home deaths for selected causes has changed from 33% in 1997 to 77% in 2001. The Anchorage-based Alaska Native Tribal Health Consortium (ANTHC) and the Alaska Native Medical Center (ANMC) have recognized the importance and success of the BBAHC program and are investigating expanding the program to other parts of Alaska. Centralizing the program in Anchorage will allow staff trained in palliative care to travel to regional Alaska Native hospitals to help train health care professionals.

PMID: 14509499 [PubMed - indexed for MEDLINE]

45: J Palliat Med. 2003 Jun;6(3):489-99.

The comprehensive care team: a description of a controlled trial of care at the beginning of the end of life.

Rabow MW, Petersen J, Schanche K, Dibble SL, McPhee SJ.

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OBJECTIVE: To describe the characteristics, acceptability, and basic efficacy of an outpatient palliative care consultation service for patients with serious illness continuing to receive treatment for their underlying disease. DESIGN:

Structured interviews of intervention patients enrolled in a prospective, nonrandomized, controlled trial. SETTING: General medicine practice in an urban, academic medical center. PATIENTS: Ninety outpatients with cancer, advanced congestive heart failure, or advanced chronic obstructive pulmonary disease. INTERVENTIONS: Palliative care consultation to primary care physicians (PCPs); educational and supportive services to patients and their families. OUTCOME MEASURES: Physician referrals, program assessment by patients, observations of clinical consultation team members. RESULTS: A majority of PCPs (61%) referred patients to the project, which provided an extensive panel of services despite significant financial constraints. Patients reported improved satisfaction with their family (85.7%), PCP (80%), and the medical center at large (65.7%) as a result of these services. Patients found discussing advance care planning difficult (66%), but desired these conversations (66%). Team members observed significant palliative care needs among this population of outpatients, however, PCPs did not implement a significant number of the consultation team's recommendations. CONCLUSIONS: Outpatient palliative care consultation and services for patients continuing to pursue treatment of their underlying disease are acceptable and helpful to patients. However, barriers to implementation of palliative care treatments in this population must be explored.

Publication Types:

Clinical Trial
Controlled Clinical Trial

PMID: 14509498 [PubMed - indexed for MEDLINE]

46: J Palliat Med. 2003 Jun;6(3):425-7.

Comment on:

J Palliat Med. 2003 Jun;6(3):345-50.

Palliative sedation and sleeping before death: a need for clinical guidelines?

Rousseau P.

Publication Types:

Comment
Editorial

PMID: 14509488 [PubMed - indexed for MEDLINE]

47: J R Soc Med. 2003 Oct;96(10):519.

Comment on:

J R Soc Med. 2003 Aug;96(8):411.

Living wills.

Wilson MB.

Publication Types:

Comment
Letter

PMID: 14519736 [PubMed - indexed for MEDLINE]

48: J R Soc Med. 2003 Oct;96(10):519-20.

Comment on:
J R Soc Med. 2003 Aug;96(8):411.

Living wills.

Astor R.

Publication Types:
Comment
Letter

PMID: 14519737 [PubMed - indexed for MEDLINE]

49: J Rural Health. 2003 Fall;19(4):461-9.

Attitudes of family physicians in Washington state toward physician-assisted suicide.

Hart LG, Norris TE, Lishner DM.

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CONTEXT: The topic of physician-assisted suicide is difficult and controversial. With recent laws allowing physicians to assist in a terminally ill patient's suicide under certain circumstances, the debate concerning the appropriate and ethical role for physicians has intensified. **PURPOSE:** This paper utilizes data from a 1997 survey of family physicians (FPs) in Washington State to test two hypotheses: (1) older respondents will indicate greater opposition to physician-assisted suicide than their younger colleagues, and (2) male and rural physicians will have more negative attitudes toward physician-assisted suicide than their female and urban counterparts. **METHODS:** A questionnaire administered to all active FPs obtained a 68% response rate, with 1074 respondents found to be eligible in this study. A ZIP code system based on generalist Health Service Areas was used to designate those practicing in rural versus urban areas. **FINDINGS:** One-fourth of the respondents overall indicated support for physician-assisted suicide. When asked whether this practice should be legalized, 39% said yes, 44% said no, and 18% indicated that they did not know. Fifty-eight percent of the study sample reported that they would not include physician-assisted suicide in their practices even if it were legal. Responses disaggregated by age-groups closely paralleled the group overall. There was a significant pattern of opposition on the part of rural male respondents compared to urban female respondents. Even among those reporting support for physician-assisted suicide, many expressed reluctance about including it in

their practices. CONCLUSIONS: These findings highlight the systematic differences in FP attitudes toward one aspect of health care by gender, rural-urban practice location, and other factors.

PMID: 14526504 [PubMed - indexed for MEDLINE]

50: JAMA. 2003 Oct 15;290(15):2056.

Comment on:

JAMA. 2003 Jul 2;290(1):98-104.

Complexities in prognostication in advanced cancer: "to help them live their lives the way they want to".

Markowitz AJ, McPhee SJ.

Publication Types:
Comment

PMID: 14559960 [PubMed - indexed for MEDLINE]

51: JAMA. 2003 Oct 15;290(15):2048-55.

Care of the dying doctor: on the other end of the stethoscope.

Fromme E, Billings JA.

Massachusetts General Hospital Palliative Care Service and the Harvard Medical School Center for Palliative Care and Oregon Health and Science University, Boston, MA 02114, USA.

The challenges of caring for a dying doctor reflect both common issues in helping the terminally ill and unique problems in working with a physician-patient. The dying doctor must deal with a familiar environment and set of problems from a radically different perspective and must negotiate overlapping and conflicting personal and professional roles. Some of the cardinal virtues of physicians--professional identity, expertise, perfectionism, selflessness, and stoicism--may pose both strengths and liabilities in the patient's role. The treating physicians may also encounter new strains in caring for a colleague. They must guard against both overinvolvement and underinvolvement, and, as with all dying persons, they must serve as a guide through unfamiliar territory for dying patient and family--a companion who is not afraid to listen to or explore the most upsetting matters, a person who can speak frankly when others may be ignoring "the horse on the dining room table." The case of Dr B, an internist dying of myelofibrosis and congestive heart failure, whose son is also a physician, offers the reader the opportunity to reflect on these challenges and to draw lessons about how to best care for fellow physicians at a time of great need. We suggest strategies for negotiating the patient-physician relationship when the patient is also a physician.

PMID: 14559959 [PubMed - indexed for MEDLINE]

52: Kennedy Inst Ethics J. 2003 Jun;13(2):141-68.

Revisiting the problem of Jewish bioethics: the case of terminal care.

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This paper examines the main Jewish sources relevant to end-of-life ethics, two Talmudic stories, the early modern code of law (Shulhan Aruch), and contemporary Halakhaic (religious law) responsa. Some Orthodox rabbis object to the use of artificial life support that prolongs the life of a dying patient and permit its active discontinuation when the patient is suffering. Other rabbis believe that every medical measure must be taken in order to prolong life. The context of the discussion is the most recent release of the "Steinberg Report," which proposes a law regulating end-of-life issues in Israel. It is argued that the Orthodox rabbis base their views on a strongly positivist concept of religious law. The rabbis deliberate the law as a manifestation of the will of God and try to stretch the law as much as possible in order to benefit the patient, even when it is good for the patient to die. Direct and active actions that kill are prohibited; certain forms of passive euthanasia and contrivances that terminate life support without needing direct human action are accepted.

PMID: 14570008 [PubMed - indexed for MEDLINE]

53: Kennedy Inst Ethics J. 2003 Jun;13(2):119-39.

Persistent vegetative state, prospective thinking, and advance directives.

Mappes TA.

Frostburg State University, Frostburg, MD, USA.

This article begins with a discussion of persistent vegetative state (PVS), focusing on concerns related to both diagnosis and prognosis and paying special attention to the 1994 Multi-Society Task Force report on the medical aspects of PVS. The article explores the impact of diagnostic and prognostic uncertainties on prospective thinking regarding the possibility of PVS and considers the closely related question of how prospective thinkers might craft advance directives in order to deal most effectively with this possibility.

PMID: 14570002 [PubMed - indexed for MEDLINE]

54: Lancet Neurol. 2003 Oct;2(10):583.

Comment on:

Lancet Neurol. 2003 Oct;2(10):637-43.

Right to die--right or wrong?

[No authors listed]

Publication Types:

Comment

Editorial

PMID: 14505577 [PubMed - indexed for MEDLINE]

55: Lancet Neurol. 2003 Oct;2(10):637-43.

Comment in:

Lancet Neurol. 2003 Oct;2(10):583.

Physician-assisted death: dying with dignity?

Reagan P, Hurst R, Cook L, Zylicz Z, Otlowski M, Veldink JH, van den Berg LH, Wokke JH.

PMID: 14505588 [PubMed - indexed for MEDLINE]

56: Med J Aust. 2003 Sep 15;179(6 Suppl):S14-6.

Approaching death in multicultural Australia.

Lickiss JN.

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Culture is a system of shared ideas, concepts, rules and meanings that underlies the way we live--and approach death. Cultural diversity refers to more than ethnic diversity: age, gender, sexual preference, capabilities, education, place of residence, and occupation (including the health professions) contribute to diversity of culture. Clinical decision making involves values and ethical principles, which are influenced by culture--not only of the patient but also of the carers and health professionals. Care of patients approaching death involves the whole healthcare system--but may need, from time to time, palliative care specialist input, including specialised cultural competence. Education and training of palliative medicine specialists in Australia needs to include a focus on cultural competence.

PMID: 12964928 [PubMed - indexed for MEDLINE]

57: Med J Aust. 2003 Sep 15;179(6 Suppl):S38-40.

Palliative care at home: general practitioners working with palliative care teams.

Yuen KJ, Behrndt MM, Jacklyn C, Mitchell GK.

Cancer Foundation Cottage Hospice, and Royal Perth Hospital, Shenton Park, WA 6008. kyuen@cancerwa.asn.au

Home care is the preferred option for most people with a terminal illness. Providing home care relies on good community-based services, and a general practice workforce competent in palliative care practice and willing to accommodate patients' needs. Structured palliative care training of general practitioners is needed at undergraduate and postgraduate level, with attention to barriers to teamwork and communication. Good palliative care can be delivered to patients at home by GPs (supported by specialist palliative care teams) and community nurses, with access to an inpatient facility when required. To optimise patient care, careful planning and good communication between all members of the healthcare team is crucial.

PMID: 12964936 [PubMed - indexed for MEDLINE]

58: Med J Aust. 2003 Sep 15;179(6 Suppl):S44-6.

Advances in palliative care relevant to the wider delivery of healthcare.

Good PD.

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Phillip.Good@mater.health.nsw.gov.au

The availability of a variety of opioids, together with the discovery of new uses for old drugs (such as ketamine), assists individualised pain management in palliative care. Experience in palliative care provides reassurance that the effective use of opioids and sedatives does not accelerate the approach of death. In taking patient histories, recognising the spiritual component of life experience enlarges the focus of care. Interdisciplinary care brings many different insights to care situations in a prospective and cooperative way. Models of bereavement care established in palliative care units deserve wider implementation in medicine. An "experiential" model of medical student education encourages a focus on the whole experience of patients and their journey with their carers.

PMID: 12964938 [PubMed - indexed for MEDLINE]

59: Nurs Ethics. 2003 Sep;10(5):497-503.

The death of a patient with AIDS in Turkey: thoughts on the ethical dimensions.

Namal A.

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A Turkish patient with AIDS attempted to commit suicide. Turkey is one of the countries where AIDS education in society and for health personnel has started rather late. This article documents what this patient, his sister and his friends, who helped him to survive for a short while, experienced in the hospital environment. This is a real case history and should be considered from various aspects because suicide was attempted by a person with AIDS who was near the terminal stage. The patient's friends made a remarkable effort to help him to survive. They were unsure about what to do because they had not respected his wishes and they experienced deep alienation because of the extremely negative attitude of the medical staff.

PMID: 14529116 [PubMed - indexed for MEDLINE]

60: Nurs Stand. 2003 Aug 6-12;17(47):27.

Taking care of dying.

Wright S.

St Martin's College Lancaster.

PMID: 13677727 [PubMed - indexed for MEDLINE]

61: Nurse Pract. 2003 Aug;28(8):7.

Comment on:

Nurse Pract. 2003 May;28(5):11.

Oncologists and end-of-life care.

Cochran H.

Publication Types:

Comment

Letter

PMID: 12902935 [PubMed - indexed for MEDLINE]

62: Nursing. 2003 Aug;33(8):73.

When a patient revokes an advance directive.

[No authors listed]

PMID: 12918497 [PubMed - indexed for MEDLINE]

63: Nursing. 2003 Aug;33(8):22.

Assessing pain at the end of life.

Wentz JD.

Jewish Hospital College of Nursing and Allied Health, St. Louis, MO, USA.

PMID: 12918475 [PubMed - indexed for MEDLINE]

64: Nursing. 2003 Aug;33(8):12; author reply 12.

Concentrated pain relief.

Shockey P.

Publication Types:

Letter

PMID: 12918464 [PubMed - indexed for MEDLINE]

65: NY Times (Print). 2003 Aug 2;;A7.

Doctor-assisted deaths increase in Europe.

[No authors listed]

Publication Types:

Newspaper Article

PMID: 14515850 [PubMed - indexed for MEDLINE]

66: NY Times (Print). 2003 Jul 31;;A23.

First study on patients who fast to end lives.

McNeil DG.

Publication Types:

Newspaper Article

PMID: 14515848 [PubMed - indexed for MEDLINE]

67: NY Times (Print). 2003 Jul 19;;B1, B2.

Patients whose final wishes go unsaid put doctors in a bind.

Kleinfield NR.

Publication Types:
Newspaper Article

PMID: 14515847 [PubMed - indexed for MEDLINE]

68: Palliat Med. 2003 Sep;17(6):520-6.

Difficulties encountered by nurses in the care of terminally ill cancer patients in general hospitals in Japan.

Sasahara T, Miyashita M, Kawa M, Kazuma K.

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The aim of this study was to investigate the difficulties encountered by nurses who have cared for terminally ill cancer patients at general hospitals. To collect data, a survey by questionnaire was self-administered. The respondents were 375 nurses and the response rate was 70.2%. Factor analysis was conducted on 80 items related to the difficulties encountered by nurses who have cared for terminally ill cancer patients to allow reasonable item reduction and to explore better domains. Two items were excluded and the results revealed eight underlying domains: 'Communication with patients and families', 'Knowledge and skill of nurses', 'Treatment and informed consent (IC)', 'Personal issues', 'Collaboration as a team including patients and families', 'Environment and system', 'Collaboration among nurses', and 'Near-death issues'. Cronbach's alpha coefficients for each domain ranged from 0.77 to 0.93. The results showed that nurses working at general hospitals have experienced a high degree of difficulty overall while caring for the dying, particularly with communication with patients and families. It was concluded that this study was useful in determining the specific areas where nursing education and research should be focused.

Publication Types:
Multicenter Study

PMID: 14526886 [PubMed - indexed for MEDLINE]

69: Palliat Med. 2003 Sep;17(6):514-9.

Palliative care for patients with end-stage renal failure: reflections from Central Australia.

Fried O.

Northern Territory Department of Health and Community Services, Alice Springs, Australia. ofrafried@bigpond.com

This paper explores palliative care issues for Australian Aboriginal patients with end-stage renal failure. Renal disease is epidemic amongst Aboriginal Australians. The Central Australian Palliative Care Service, based in the remote town of Alice Springs, sees a high proportion of renal patients, with different demographic characteristics to those seen in urban palliative care services. A case history illustrates distinctive concerns for local service provision, including communication issues, cultural requirements for maximizing quality of life, and the need to provide care in remote locations. Palliation for end-stage renal failure (ESRF) patients should be based on standard principles, but modified in accordance with local practical requirements and community needs.

PMID: 14526885 [PubMed - indexed for MEDLINE]

70: Pharos Alpha Omega Alpha Honor Med Soc. 2003 Summer;66(3):4-7.

The evolution of palliative care.

Saunders C.

St. Christopher's Hospice. info@stchristophers.org.uk

PMID: 14520783 [PubMed - indexed for MEDLINE]

71: Prehosp Emerg Care. 2003 Jul-Sep;7(3):303-6.

Resuscitation of residents with do not resuscitate orders in long-term care facilities.

Becker LJ, Yeargin K, Rea TD, Owens M, Eisenberg MS.

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BACKGROUND: A considerable number of emergency medical services (EMS) responses for cardiac arrest occur in long-term care facilities. In some instances, these responses are for residents who have expressed wishes not to be resuscitated by signing a do not resuscitate (DNR) order. **OBJECTIVES:** To assess the magnitude of EMS use for cardiac arrest in long-term care facilities for residents with DNR orders and to determine reasons why EMS is called. **METHODS:** A retrospective study was conducted using data collected from medical incident reports between July 1999 and December 2000 for all persons experiencing cardiac arrest in long-term care facilities defined as nursing homes, adult family homes, and assisted-living centers in King County, Washington, excluding Seattle. The authors also surveyed facilities to determine their policies for calling 9-1-1 in the event of cardiac arrest. **Results.** Of the 392 cardiac arrests in long-term care facilities to which EMS responded, 139 (35%) of the residents had DNR orders. Of these 139, 29 (21%) received attempted resuscitation by EMS. The problem appeared to be greater among nursing homes and adult family homes than in assisted-living centers. Among nursing homes, the primary reason for an EMS

call was concern for validity of the DNR order, whereas among adult family homes, the primary concern was appropriate medical authority to declare death. CONCLUSION: Efforts to clarify existing regulations, streamline the DNR transfer process, and improve communication between EMS and long-term care facilities may result in better fulfillment of residents' end-of-life wishes and a saving of EMS resources.

PMID: 12879377 [PubMed - indexed for MEDLINE]

72: Prof Nurse. 2003 Aug;18(12):710-3.

Oncology nurses' perceptions of their role in resuscitation decisions.

Bass M.

Ipswich Hospital NHS Trust, Suffolk.

A group of nurses working in a unit for oncology and haematology patients took part in a study on how they perceived their role in resuscitation decisions. Although many of the nurses expressed a desire to be involved in helping patients exercise choice in this area, in practice few nurses felt able to raise the subject with patients or to act as their advocate with doctors.

PMID: 12955945 [PubMed - indexed for MEDLINE]

73: Psychol Public Policy Law. 2000 Jun;6(2):416-33.

Factors to consider before participating in a hastened death: issues for medical professionals.

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An emerging problem that health professionals face in working with terminally ill patients is how to respond to the concerns and conflicts that emerge near the end of life. Most important are those that challenge the traditional healing, caring and therapeutic roles. Among these, perhaps none has drawn as much attention as the issue of physician-assisted dying--particularly what has been termed assisted suicide. Although the ethics of assisted dying have been actively debated by ethicists for decades, the topic is now being discussed with increasing frequency in medical, psychiatric, psychological, and legal journals. Interest has been driven by the interrelationship of changing public opinion, demographics, and the nature of the dying process; admissions of assistance by numerous physicians; and several statewide attempts at legal change, culminating in a successful voters' initiative in Oregon.

PMID: 12953680 [PubMed - indexed for MEDLINE]

74: Psychol Public Policy Law. 2000 Jun;6(2):382-7.

Misguided guidelines.

Burt RA.

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The proposed guidelines would require detailed, probing inquiry into motivation for choosing assisted suicide. This is an appropriate requirement in principle. In practice, it will be virtually impossible to carry out this inquiry within likely statutory time limits. Evaluators most likely will either reject the guidelines as impractical or give them merely perfunctory observance. There is, moreover, an inherent tension in the evaluator's relationship with the patient between empathy and impersonal distancing that the guidelines do not adequately acknowledge; this tension necessarily compromises the evaluator's ability to apply the guidelines in the probing, detailed manner they envision. The guidelines provide false comfort that physician-assisted suicide can be carried out with adequately sensitive monitoring of voluntariness and mental competence.

PMID: 12953677 [PubMed - indexed for MEDLINE]

75: Psychol Public Policy Law. 2000 Jun;6(2):402-7.

Bureaucratizing suicide.

Youngner SJ.

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Although helpful in many ways, the Guidelines for Assessing Mental Capacity and Impaired Judgment fall short in 3 areas. First, the term capacity is poorly defined and explicated. Second, the inevitable role of the evaluator's own values is given short shrift. Finally, the Guidelines rely too heavily on lists and formal test without guidance about what is most important. This failure threatens to further burden dying patients with unwanted and unnecessary bureaucratic intrusion.

PMID: 12953679 [PubMed - indexed for MEDLINE]

76: Qual Health Res. 2003 Oct;13(8):1039-62.

Meaning and agency in discussing end-of-life care: a study of elderly veterans' values and interpretations.

Young AJ, Ofori-Boateng T, Rodriguez KL, Plowman JL.

VA Pittsburgh Healthcare System's Geriatric Research, Education, and Clinical Center (GRECC), Department of Neurology, University of Pittsburgh School of Medicine, Pennsylvania, USA.

The authors of this exploratory study used textual analysis of transcribed interviews to examine the mental constructs that individuals form around advance care terminology and to learn how elderly veterans conceptualize the language used in the Veterans Administration advance directive. They found that respondents often negotiated meaning by drawing on rigid schemas, specific mental constructs already in place: The Lord's Will, Machine Talk, Being a Burden, and Being Productive. The authors also examined the transcripts for agency. In addition to assigning external agency for end-of-life care decisions, respondents often expressed a complex interaction of "self" and "other" agency. These results challenge us to develop communication methods that allow patients to claim agency and participate fully in decisions regarding their health care, especially at the end of life.

PMID: 14556418 [PubMed - in process]

77: Resuscitation. 2003 Jun;57(3):311-2; author reply 312-3.

Comment on:

Resuscitation. 2002 Dec;55(3):235-40.

Medical end-of-life decisions in Norway.

Laake JH, Stubhaug A.

Publication Types:

Comment

Letter

PMID: 12804809 [PubMed - indexed for MEDLINE]

78: S C Nurse. 2003 Apr-Jun;10(2):13.

Emergency Medical Services DNR orders: what you always needed to know.

Chase P.

PMID: 13677105 [PubMed - indexed for MEDLINE]

79: Soc Sci Med. 2003 Nov;57(9):1609-20.

Physicians' experiences of caring for late-stage HIV patients in the post-HAART era: challenges and adaptations.

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As medical treatment for AIDS has become more complex, the need for good palliative and end-of-life care has also increased for patients with advanced disease. Such care is often inadequate, especially among low-income, ethnic minority patients. The current study investigated physicians' experiences with caring for dying HIV patients in an underserved, inner city community in the Bronx, NY. The goals of the study included: (1) to investigate the barriers to effective end-of-life care for HIV patients; and (2) to examine physicians' experiences of role hindrance and frustration in caring for dying patients in the era of HAART. Qualitative, open-ended interviews were conducted with 16 physicians. Physicians identified two core, prescriptive myths shaping their care for patients with HIV. The 'Good Doctor Myth' equates good medical care with the delivery of efficacious biomedical care. The role of the physician is defined as technical curer, while the patient's role is limited to consultation and compliance. The 'Good Death Myth' envisions an ideal death which is acknowledged, organized, and pain free: the role of the physician is defined as that of comforter and supporter in the dying process. Role expectations associated with these myths were often disappointed. First, late-stage patients refused to adhere to treatment and were thus dying "unnecessarily." Second, patients often refused to acknowledge, accept, or plan for the end of life and as a result died painful, chaotic deaths. These realities presented intense psychological and practical challenges for providers. Adaptive coping included both behavioral and cognitive strategies. Successful adaptation resulted in "positive engagement," experienced by participants as a continuing sense of fascination, gratification, and joy. Less successful adaptation could result in detachment or anger. Participants believed that engagement had a powerful impact on patient care. Working with dying HIV patients in the post-HAART era of efficacious treatment challenges physician's cherished roles and values. Physicians adapt to the challenge through a variety of cognitive and behavioral strategies. The failure to adapt successfully has psychological consequences for providers that may impact patient care.

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80: Swiss Med Wkly. 2003 May 31;133(21-22):310-7.

748 cases of suicide assisted by a Swiss right-to-die organisation.

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BACKGROUND AND METHODS: In Switzerland, nonmedical right-to-die organisations offer instruction and personal guidance in committing suicide to members suffering from incurable diseases. Suicide is usually committed with a lethal dose of barbiturates prescribed by a physician. This study is a retrospective analysis of all case files of assisted suicide kept during the period 1990-2000 by "Exit Deutsche Schweiz", the largest Swiss right-to-die organisation.

RESULTS: Between 1990 and 2000 Exit assisted in 748 suicides among Swiss residents (0.1% of total deaths, 4.8% of total suicides). 54.4% of the deceased

were women. Mean age at death was 73 years in males and 72 years in females (range 18-101 years). Assisted suicide was over-proportionately represented in the German-speaking ($p < 0.0001$), more urbanised ($p < 0.0001$), predominantly Protestant ($p < 0.0001$) cantons. Over the study period the annual number of Exit deaths more than tripled ($p < 0.0001$). Of the 331 who died in Canton Zurich, 47.4% had cancer, 11.8% cardiovascular/respiratory disease, 12.4% neurological disease and 7.3% HIV/AIDS. The remaining 21.1% suffered from other, usually non-fatal conditions; 76% of these were women. There were no significant changes in sex, age and distribution of diagnoses during the study period. At first all the lethal substances were taken orally, but by the end of the study period 14% were administered via infusion or PEG catheter. All assisted suicides in the City of Zurich were duly notified to the authorities. CONCLUSIONS: The number of suicides assisted by "Exit Deutsche Schweiz" and the practices followed markedly expanded over this time. There was no apparent relaxation of the indications for assisted suicide. Notification of the authorities appeared to be total.

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Characteristics of hospice care discharges and their length of service: United States, 2000.

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OBJECTIVE: To obtain the maximum benefit from hospice, a person should receive hospice services for at least 30 days. For many Americans, this goal is not being met. This report presents data on hospice care discharges for 2000. Selected trend data are also presented. METHODS: Data are from the National Home and Hospice Care Survey. The data presented are numbers and percents by selected discharge characteristics. Length of service measures include average and median length of service and length of service intervals. RESULTS AND CONCLUSIONS: There were 621,100 discharges from hospice care in 2000. The typical discharge was elderly, white, lived in a private or semiprivate residence with a caregiver to whom they were related, and died while in hospice care. The primary source of payment was Medicare. Most received three or more services, were seen by three or more service providers, received help from the hospice with at least one activity of daily living (ADL), were incontinent, and had mobility limitation. Cancer is the most common primary admission diagnosis, but the proportion decreased from 75 percent in 1992 to 58 percent in 2000. Most of the discharges did not receive timely care. Sixty-three percent of discharges received hospice care for less than 30 days. The average length of service was 46.9 days, and the median length of service was 15.6 days. Shorter lengths of service occurred for those who were living in institutions, did not receive help from the agency with ADLs, had a lower level of mobility limitation, and had a primary admission diagnosis of cerebrovascular disease. Of the noninstitutionalized discharges, those whose primary caregiver was a spouse had shorter lengths of service than those who were cared for by a child.

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82: Z Gerontol Geriatr. 2003 Oct;36(5):339-46.

Technology and "natural death": A study of older people.

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This paper reports a qualitative study in which the aim was to examine older peoples' beliefs and risk perceptions regarding the use of innovative health technologies in end-of-life care and to relate these beliefs to their ideas about 'natural death'. Pictures, story boards and media extracts were used during interviews and focus groups, and the research team was assisted by an advisory group which included participants. Seventy-seven older people from three age cohorts (65-74; 75-84; 85 years and over) and from three contrasting areas of Sheffield, UK took part. Key messages are for the need to ensure that 'life prolonging' and 'basic care' technologies are provided in ways that respect a variety of understandings about love, comfort, obligation and burden during dying. The study highlights: the role that older people have in caring for the dying and their needs for support and training; information needs about issues of ethics, clinical practice and advance care planning; and the willingness of older research participants to discuss these matters and to enjoy the process of so doing. Developing a programme of public education and information was identified as an issue which should be addressed urgently if older people and their family carers are to be better equipped to make informed choices about these aspects of care. The study draws together issues previously considered under the largely separate remits of palliative care and gerontology. It is being used to provide advice on palliative and end-of-life care, especially to nursing and medical practitioners and to voluntary sector organisations as they begin to assess the need for action in this field.

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