



END OF LIFE CARE BIBLIOGRAPHY August 2004

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

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

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

PMID: 15277135 [PubMed - in process]

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

End-of-Life Care in the Curriculum: A National Study of Medical Education Deans.

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

PMID: 15277133 [PubMed - in process]

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

An Innovative, Longitudinal Program to Teach Residents about End-of-Life Care.

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

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

PMID: 15277130 [PubMed - in process]

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

Geriatric failure to thrive.

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

PMID: 15291092 [PubMed - in process]

5: Am J Alzheimers Dis Other Demen. 2004 Mar-Apr;19(2):94-104.

Hospice use for the patient with advanced Alzheimer's disease: the role of the geriatric psychiatrist.

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Advanced Alzheimer's disease (AD) can place an immense burden on caregivers as they struggle to provide end-of-life (EOL) care for the patient. Palliative care, as delivered by hospice, provides a viable solution. Hospice maintains the patient's quality of life (QOL) and helps the family during the grieving process. However, many providers are not familiar with hospice and its care for advanced AD patients. Geriatric psychiatrists can be central in implementing hospice, and they can remain an important part of the care once it is in place. A principal clinical challenge is establishing the six-month prognosis for such patients, which is a prerequisite for initiating hospice admission.

PMID: 15106390 [PubMed - indexed for MEDLINE]

6: Am J Crit Care. 2004 Jul;13(4):328-34.

Documentation on withdrawal of life support in adult patients in the intensive care unit.

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BACKGROUND: Patients' charts have been a source of data for retrospective studies of the quality of end-of-life care. In the intensive care unit, most patients die after withdrawal of life support. Chart reviews of this process could be used not only to assess the quality of documentation but also to provide information for quality improvement and research. **OBJECTIVE:** To assess the documentation of end-of-life care of patients and their families by care providers in the intensive care unit. **METHOD:** Charts of 50 adult patients who died in the intensive care unit at a large midwestern hospital after initiation of withdrawal of life support (primarily mechanical ventilation) were reviewed. A form developed for the study was used for data collection. **RESULTS:** The initiation of the decision making for withdrawal was documented in all 50 charts. Sixteen charts (32%) had no information on advance directives. Eight charts (16%) had no documentation on resuscitation status. About two thirds of the charts documented nurses' participation during the withdrawal process; only one tenth documented physicians' participation. A total of 13 charts (26%) had no information on the time of initiation of the withdrawal process, and 11 (22%) had no documentation of medications administered for withdrawal. Thirty-seven charts (74%) had information on whether the patient was or was not extubated during withdrawal. **CONCLUSION:** Comprehensive documentation of end-of-life care is lacking.

PMID: 15293586 [PubMed - in process]

7: Am J Forensic Med Pathol. 2004 Jun;25(2):150-5.

Withholding and withdrawing of life support: a medicolegal dilemma.

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The developments in medicine in general and the technology of life support in particular have provided the means of maintaining organ function for prolonged periods of time. However, there are many situations where life-sustaining treatment in an intensive care unit (ICU) may lead to a death with lingering and suffering of the patient, as well as burdening their family. Although often equated, withholding and/or withdrawing life-prolonging treatments that allow the patient to die needs to be differentiated from the physician-assisted suicides and euthanasia that involve the active ending of life. There is a difference between an unintended but accepted consequence of forgoing therapy and an intended result of death from suicide or euthanasia. The present-day physicians view most patient deaths as an inevitable process secondary to disorders unresponsive to treatment and/or multiple organ dysfunction syndromes. The large majority of patients dying in ICUs today succumb not after cardiopulmonary resuscitation, but rather, after the forgoing of life-sustaining treatment. Such approach has frequently caused families, institutions, and conservators of patients to resort to judicial fiat for resolution.

Publication Types:

Review

Review, Tutorial

PMID: 15166768 [PubMed - indexed for MEDLINE]

8: Am J Ment Retard. 2004 Sep;109(5):421-8.

Status of end of life care in organizations providing services for older people with a developmental disability.

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Marist College.

Volunteers of America conducted a national survey of directors of 500 organizations providing services to older people with an intellectual disability in order to establish a baseline for assessing current status of end of life care. The questionnaire contained 56 questions. The return rate was 32% (N = 160). Data analysis provided an overview of organizational needs, resource allocations, end of life care services currently provided, obstacles to care, methods for monitoring such care, and existing and recommended strategies for improving this care. Results underscored the needs for practical guidelines and resources, increased staffing and training, and policy-level reduction of obstacles to promote improved end of life care.

PMID: 15298520 [PubMed - in process]

9: Am J Nurs. 2004 Jul;104(7):40-7; quiz 48.

Oral complications at the end of life.

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Publication Types:

Case Reports
Review
Review, Tutorial

PMID: 15243256 [PubMed - indexed for MEDLINE]

10: Am J Nurs. 2004 Jul;104(7):39.

Reflections: the ice-bag incident.

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PMID: 15243255 [PubMed - indexed for MEDLINE]

11: Am J Surg. 2004 Jul;188(1):98-101.

Advance directive use among patients undergoing high-risk operations.

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BACKGROUND: The Patient Self-Determination Act requires that patients entering hospitals be asked if they have an advance directive. This has led to increased awareness of advance directives, yet surgeons have paid little attention to their use among patients undergoing even major surgery. We sought to evaluate the use of advance directives in patients undergoing pancreaticoduodenectomy and esophagectomy. **METHODS:** Patients undergoing these operations between 1996 and 2001 at a university teaching hospital were identified and reviewed for statement of advance directive, its presence in the chart, and impact on patient care. **RESULTS:** A total of 252 patients met inclusion criteria. The number of patients with an advance directive increased, but had little impact on patient care. **CONCLUSIONS:** More patients having major surgery have advance directives, but the number present in the medical record remains low. Further attention to advance directives would foster increased communication between surgeons and patients and extend patient autonomy.

PMID: 15219496 [PubMed - indexed for MEDLINE]

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

Physician reports of terminal sedation without hydration or nutrition for

patients nearing death in the Netherlands.

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

PMID: 15289214 [PubMed - in process]

13: Ann Intern Med. 2004 Jul 20;141(2):140.

Comment on:

Ann Intern Med. 2004 Jul 20;141(2):113-7.

Summaries for patients. Do living wills affect the setting where people die in the United States?

[No authors listed]

Publication Types:

Comment

Patient Education Handout

PMID: 15262683 [PubMed - indexed for MEDLINE]

14: Ann Intern Med. 2004 Jul 20;141(2):159-60.

Comment on:

Ann Intern Med. 2004 Jul 20;141(2):113-7.

Advance directives: time to move on.

Teno JM.

Publication Types:

Comment

Editorial

PMID: 15262674 [PubMed - indexed for MEDLINE]

15: Ann Intern Med. 2004 Jul 20;141(2):113-7.

Comment in:

Ann Intern Med. 2004 Jul 20;141(2):159-60.

Ann Intern Med. 2004 Jul 20;141(2):140.

Brief communication: the relationship between having a living will and dying in place.

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BACKGROUND: Living wills, a type of advance directive, are promoted as a way for patients to document preferences for life-sustaining treatments should they become incompetent. Previous research, however, has found that these documents do not guide decision making in the hospital. **OBJECTIVE:** To test the hypothesis that people with living wills are less likely to die in a hospital than in their residence before death. **DESIGN:** Secondary analysis of data from a nationally representative longitudinal study. **SETTING:** Publicly available data from the Asset and Health Dynamics Among the Oldest Old (AHEAD) study. **PATIENTS:** People older than 70 years of age living in the community in 1993 who died between 1993 and 1995. **MEASUREMENTS:** Self-report and proxy informant interviews conducted in 1993 and 1995. **RESULTS:** Having a living will was associated with lower probability of dying in a hospital for nursing home residents and people living in the community. For people living in the community, the probability of in-hospital death decreased from 0.65 (95% CI, 0.58 to 0.71) to 0.52 (CI, 0.42 to 0.62). For people living in nursing homes, the probability of in-hospital death decreased from 0.35 (CI, 0.23 to 0.49) to 0.13 (CI, 0.07 to 0.22). **LIMITATIONS:** Retrospective survey data do not contain detailed clinical information on whether the living will was consulted. **CONCLUSION:** Living wills are associated with dying in place rather than in a hospital. This implies that previous research examining only people who died in a hospital suffers from selection bias. During advance care planning, physicians should discuss patients' preferences for location of death.

PMID: 15262666 [PubMed - indexed for MEDLINE]

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

Resuscitating advance directives.

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

PMID: 15277279 [PubMed - in process]

17: BMC Med Ethics. 2002 Aug 12;3(1):E3.

Comment in:

Curr Surg. 2003 Jul-Aug;60(4):360-4.

Consensus guidelines on analgesia and sedation in dying intensive care unit patients.

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BACKGROUND: Intensivists must provide enough analgesia and sedation to ensure dying patients receive good palliative care. However, if it is perceived that too much is given, they risk prosecution for committing euthanasia. The goal of this study is to develop consensus guidelines on analgesia and sedation in dying intensive care unit patients that help distinguish palliative care from euthanasia. **METHODS:** Using the Delphi technique, panelists rated levels of agreement with statements describing how analgesics and sedatives should be given to dying ICU patients and how palliative care should be distinguished from euthanasia. Participants were drawn from 3 panels: 1) Canadian Academic Adult Intensive Care Fellowship program directors and Intensive Care division chiefs

(N = 9); 2) Deputy chief provincial coroners (N = 5); 3) Validation panel of Intensivists attending the Canadian Critical Care Trials Group meeting (N = 12). RESULTS: After three Delphi rounds, consensus was achieved on 16 statements encompassing the role of palliative care in the intensive care unit, the management of pain and suffering, current areas of controversy, and ways of improving palliative care in the ICU. CONCLUSION: Consensus guidelines were developed to guide the administration of analgesics and sedatives to dying ICU patients and to help distinguish palliative care from euthanasia.

PMID: 12171602 [PubMed - indexed for MEDLINE]

18: Can J Psychiatry. 2004 Jun;49(6):366-72.

Psychotherapeutic interventions at the end of life: a focus on meaning and spirituality.

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Medical and psychological discourse on end-of-life care has steadily shifted over the years from focusing primarily on symptom control and pain management to incorporating more person-centred approaches to patient care. Such approaches underscore the significance of spirituality and meaning making as important resources for coping with emotional and existential suffering as one nears death. Though existential themes are omnipresent in end-of-life care, little has been written about their foundations or import for palliative care practitioners and patients in need. In this article, we explore the existential foundations of meaning and spirituality in light of terminal illness and palliative care. We discuss existential themes in terms of patients' awareness of death and search for meaning and practitioners' promotion of personal agency and responsibility as patients face life-and-death issues. Viktor Frankl's existential logotherapy is discussed in light of emerging psychotherapeutic interventions. Meaning-centred group therapy is one such novel modality that has successfully integrated themes of meaning and spirituality into end-of-life care. We further explore spiritual and existential themes through this meaning-oriented approach that encourages dying patients to find meaning and purpose in living until their death.

PMID: 15283531 [PubMed - in process]

19: Chest. 2004 Jul;126(1):286-93.

Narcotic and benzodiazepine use after withdrawal of life support: association with time to death?

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OBJECTIVE: To determine whether the dose of narcotics and benzodiazepines is associated with length of time from mechanical ventilation withdrawal to death in the setting of withdrawal of life-sustaining treatment in the ICU. DESIGN: Retrospective chart review. SETTING: University-affiliated, level I trauma center. PATIENTS: Consecutive critically ill patients who had mechanical ventilation withdrawn and subsequently died in the ICU during two study time periods. RESULTS: There were 75 eligible patients with a mean age of 59 years. The primary ICU admission diagnoses included intracranial hemorrhage (37%), trauma (27%), acute respiratory failure (27%), and acute renal failure (20%). Patients died during a median of 35 min (range, 1 to 890 min) after ventilator withdrawal. On average, 16.2 mg/h opiates in morphine equivalents and 7.5 mg/h benzodiazepine in lorazepam equivalents were administered during the time period starting 1 h before ventilator withdrawal and ending at death. There was no statistically significant relationship between the average hourly narcotic and benzodiazepine use during the 1-h period prior to ventilator withdrawal until death, and the time from ventilator withdrawal to death. The restriction of medication assessment in the last 2 h of life showed an inverse association between the use of benzodiazepines and time to death. For every 1 mg/h increase in benzodiazepine use, time to death was increased by 13 min ($p = 0.015$). There was no relationship between narcotic dose and time to death during the last 2 h of life ($p = 0.11$). CONCLUSIONS: We found no evidence that the use of narcotics or benzodiazepines to treat discomfort after the withdrawal of life support hastens death in critically ill patients at our center. Clinicians should strive to control patient symptoms in this setting and should document the rationale for escalating drug doses.

PMID: 15249473 [PubMed - indexed for MEDLINE]

20: Clin Cornerstone. 2004;6(1):43-9.

End-of-life care for ethnic minority groups.

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Death and dying are profound events that bring into focus important ethical and medical questions for all patients, whatever their cultural background. For ethnic minority groups and their families, specific issues or barriers may arise related to culturally appropriate health care practices, cultural or religious differences, diverse health beliefs, and access to services for care and support during end-of-life conditions. National policy and local initiatives in both the United States and the United Kingdom support the development of services that address the care of ethnic minorities. This article examines end-of-life care for ethnic minority groups.

PMID: 15255277 [PubMed - in process]

21: Clin Med. 2004 Jan-Feb;4(1):39-44.

Patterns of dying: palliative care for non-malignant disease.

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As awareness grows of the palliative care needs of those diagnosed with advanced life-threatening illness other than cancer, consideration needs to be given to how to address these needs. This paper focuses on palliative care for those with such diagnoses by describing variations in illness trajectory according to diagnosis, and exploring how this may affect provision of palliative care.

PMID: 14998265 [PubMed - indexed for MEDLINE]

22: Crit Care Clin. 2004 Jul;20(3):525-40, xi.

The dying patient in the ICU: role of the interdisciplinary team.

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Expert opinion supports the application of broad interdisciplinary team approaches to the care of the dying patient in the intensive care unit (ICU). Current literature contains many suggestions about how core team members-physicians, nurses, and patients/family members-could systematically enhance interdisciplinary collaboration in the care of the dying patient. In the few studies of ICU interdisciplinary collaborative care of the dying patient, investigators have demonstrated improvement in care. In addition, ethics consultants and interdisciplinary palliative care teams, working with the core team members, have improved care for the dying. Further studies are needed to document alternative interdisciplinary models for achieving improved and durable patient, family, and provider outcomes in the care of the dying ICU patient.

Publication Types:

Review
Review, Tutorial

PMID: 15183217 [PubMed - indexed for MEDLINE]

23: Crit Care Clin. 2004 Jul;20(3):487-504, x.

Spirituality in health: the role of spirituality in critical care.

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Caring for critically ill patients requires that physicians and other health

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care professionals recognize the potential importance of spirituality in the lives of patients, families, and loved ones and in their own lives. Patients and loved ones undergo tremendous stress and suffering in facing critical illness. Professional caregivers also face similar stress and sadness. Spirituality offers people away to understand suffering and illness. Spiritual beliefs can also impact how people cope with illness. By addressing spiritual issues of patients, loved ones, and ourselves, we can create more holistic and compassionate systems of care.

Publication Types:

Review

Review, Tutorial

PMID: 15183215 [PubMed - indexed for MEDLINE]

24: Crit Care Clin. 2004 Jul;20(3):453-66, ix-x.

Caring for the family of the critically ill patient.

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Family's needs and considerations are an essential component of intensive care unit (ICU) care. Family satisfaction is related to clinician communication and decision making. Indeed, timely, honest communication is vital to the psychosocial health and satisfaction of the family. Conflict often arises within the family and between the family and the clinicians, over decision making. Again, good communication skills are critical to family satisfaction with decision making and comfort with the care received. Family members have numerous psychosocial changes, and may experience depression, anxiety, or anticipatory grief while their family member is dying in the ICU. Awareness of these conditions, providing support to the families, and allowing family access to the dying individual can assist with meeting the family's desire to see their family member have a peaceful death.

Publication Types:

Review

Review, Tutorial

PMID: 15183213 [PubMed - indexed for MEDLINE]

25: Crit Care Clin. 2004 Jul;20(3):435-51, ix.

Principles and practice of withdrawing life-sustaining treatments.

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The clinician's responsibility to the patient does not end with a decision to limit medical treatment, but continues through the dying process. Every effort should be made to ensure that withdrawing life support occurs with the same quality and attention to detail as is routinely provided when life support is initiated. Approaching the withdrawal of life support as a medical procedure provides clinicians with a recognizable framework for their actions. Key steps in this process are identifying and communicating explicit shared goals for the process, approaching withdrawal of life-sustaining treatments as a medical procedure, and preparing protocols and materials to assure consistent care. Our hope is that adopting a more formal approach to this common procedure will improve the care of patients dying in intensive care units.

Publication Types:

Review

Review, Tutorial

PMID: 15183212 [PubMed - indexed for MEDLINE]

26: Crit Care Clin. 2004 Jul;20(3):419-33, ix.

Delirium and sedation.

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Critically ill patients nearing the end of life frequently present with needs for aggressive sedation and analgesia. Optimizing patient comfort while permitting effective communication are challenging goals in this patient population. This article discusses delirium and sedation as it applies to dying patients, and provides recommendations for effective management strategies to optimize the experience of such patients at the end of life.

Publication Types:

Review

Review, Tutorial

PMID: 15183211 [PubMed - indexed for MEDLINE]

27: Crit Care Clin. 2004 Jul;20(3):403-17, viii-ix.

Terminal dyspnea and respiratory distress.

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Dyspnea is a subjective experience that can be reported by the patient. Respiratory distress is an observable corollary, and represents the physical or emotional suffering that results from the experience of dyspnea. Recognizing and understanding this subjective phenomenon poses a challenge to intensive care unit (ICU) clinicians when caring for the patient who is dying in the ICU. Dyspnea and cognitive impairment are highly prevalent in the terminally ill ICU patient. A Respiratory Distress Observation Model may provide a theoretical foundation for the assessment of this phenomenon that is grounded in emotional and autonomic domains of neurologic function. Treatment of dyspnea and respiratory distress relies on nonpharmacologic interventions and opioids and sedatives. As with pain, the treatment of dyspnea and respiratory distress relies on close evaluation of the patient and treatment to satisfactory effect. Empirical evidence suggests that quality care with control of distressing symptoms does not hasten death. Withholding opioids or sedatives in the face of unrelieved dyspnea or respiratory distress has no moral foundation.

Publication Types:

Review
Review, Tutorial

PMID: 15183210 [PubMed - indexed for MEDLINE]

28: Crit Care Clin. 2004 Jul;20(3):363-80, viii.

Communicating about end-of-life care with patients and families in the intensive care unit.

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Discussing end-of-life care and death with patients and their families is an extremely important part of providing a good quality care in the intensive care unit (ICU). Although there is little empiric research to guide ICU clinicians in the most effective way to have these conversations, there is a developing literature and experience and an increasing emphasis on making this an important part of the care we provide. Much like other ICU procedures or skills, providing sensitive and effective communication about end-of-life care requires training, practice, and supervision, as well as planning and preparation. Although different clinicians may have different approaches and should change their approach to match the needs of individual patients and their families, this article reviews some of the fundamental components to discussing end-of-life care in the ICU that should be part of the care of patients with life-threatening illnesses in the ICU.

Publication Types:

Review
Review, Tutorial

PMID: 15183208 [PubMed - indexed for MEDLINE]

29: Crit Care Clin. 2004 Jul;20(3):345-62, vii-viii.

Value and role of intensive care unit outcome prediction models in end-of-life decision making.

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In the United States, intensive care unit (ICU) admission at the end of life is commonplace. What is the value and role of ICU mortality prediction models for informing the utility of ICU care? In this article, we review the history, statistical underpinnings, and current deployment of these models in clinical care. We conclude that the use of outcome prediction models to ration care that is unlikely to provide an expected benefit is hampered by imperfect performance, the lack of real-time availability, failure to consider functional outcomes beyond survival, and physician resistance to the use of probabilistic information when death is guaranteed by the decision it informs. Among these barriers, the most important technical deficiency is the lack of automated information systems to provide outcome predictions to decision makers, and the most important research and policy agenda is to understand and address our national ambivalence toward rationing care based on any criterion.

Publication Types:

Review

Review, Tutorial

PMID: 15183207 [PubMed - indexed for MEDLINE]

30: Crit Care Med. 2004 Aug;32(8):1781-1784.

Challenges in End-of-Life Care in the ICU: Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003: Executive Summary.

Thompson BT, Cox PN, Antonelli M, Carlet JM, Cassell J, Hill NS, Hinds CJ, Pimentel JM, Reinhart K, Thijs LG.

OBJECTIVE: The purpose of the conference was to provide clinical practice guidance in end-of-life care in the ICU via answers to previously identified questions relating to variability in practice, inadequate predictive models for death, elusive knowledge of patient preferences, poor communication between staff and surrogates, insufficient or absent training of healthcare providers, the use of imprecise and insensitive terminology and incomplete documentation in the medical record. **PARTICIPANTS:** Presenters and jury were selected by the sponsoring organizations (American Thoracic Society, European Respiratory Society, European Society of Intensive Care Medicine, Society of Critical Care Medicine, Societe de Reanimation de Langue Francaise). Presenters were experts on the question they addressed. Jury members were general intensivists without special expertise in the areas considered. Experts presented in an open session

to jurors and other healthcare professionals. EVIDENCE:: Experts prepared review papers on their specific topics in advance of the conference for the jury's reference in developing the consensus statement. CONSENSUS PROCESS:: Jurors heard experts' presentations over 2 days and asked questions of the experts during the open sessions. Jury deliberation with access to the review papers occurred for 2 days following the conference. A writing committee drafted the consensus statement for review by the entire jury. The 5 sponsoring organizations reviewed the document and suggested revisions to be incorporated into the final statement. CONCLUSIONS:: Strong recommendations for research to improve end-of-life care were made. The jury advocates a shared approach to end-of-life decision-making involving the caregiver team and patient surrogates. Respect for patient autonomy and the intention to honor decisions to decline unwanted treatments should be conveyed to the family. The process is one of negotiation, and the outcome will be determined by the personalities and beliefs of the participants. Ultimately, it is the attending physician's responsibility, as leader of the team, to decide on the reasonableness of the planned action. If a conflict cannot be resolved, an ethics consultation may be helpful. The patient must be assured of a pain-free death. The jury subscribes to the moral and legal principles that prohibit administering treatments specifically designed to hasten death. The patient must be given sufficient analgesia to alleviate pain and distress; if such analgesia hastens death, this "double-effect" should not detract from the primary aim to ensure comfort.

PMID: 15286559 [PubMed - as supplied by publisher]

31: Crit Care Med. 2004 Aug;32(8):1648-53.

Factors associated with nurse assessment of the quality of dying and death in the intensive care unit.

Hodde NM, Engelberg RA, Treece PD, Steinberg KP, Curtis JR.

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OBJECTIVE:: To determine the feasibility of using nurse ratings of quality of dying and death to assess quality of end-of-life care in the intensive care unit and to determine factors associated with nurse assessment of the quality of dying and death for patients dying in the intensive care unit. DESIGN:: Prospective cohort study. SETTING:: Hospital intensive care unit. PATIENTS:: 178 patients who died in an intensive care unit during a 10-month period at one hospital. INTERVENTIONS:: Nurses completed a 14-item questionnaire measuring the quality of dying and death in the intensive care unit (QODD); standardized chart reviews were also completed. MEASUREMENTS AND MAIN RESULTS:: Five variables were found to be associated with QODD scores. Higher (better) scores were significantly associated with having someone present at the time of death ($p < .001$), having life support withdrawn ($p = .006$), having an acute diagnosis such as intracranial hemorrhage or trauma ($p = .007$), not having cardiopulmonary resuscitation in the last 8 hrs of life ($p < .001$), and being cared for by the neurosurgery or neurology services ($p = .002$). Patient age, chronic disease, and Glasgow Coma Scale scores were not associated with the 14-item QODD. Using multivariate analyses, we identified three variables as independent predictors

of the QODD score: a) not having cardiopulmonary resuscitation performed in the last 8 hrs of life; b) having someone present at the moment of death; and c) being cared for by neurosurgery or neurology services. CONCLUSIONS: Intensive care unit nurse assessment of quality of dying and death is a feasible method for obtaining quality ratings. Based on nurse assessments, this study provides evidence of some potential targets for interventions to improve the quality of dying for some patients: having someone present at the moment of death and not having cardiopulmonary resuscitation in the last 8 hrs of life. If nurse-assessed quality of dying is to be a useful tool for measuring and improving quality of end-of-life care, it is important to understand the factors associated with nurse ratings.

PMID: 15286539 [PubMed - in process]

32: Crit Care Med. 2004 Jul;32(7):1631-2.

Comment on:

Crit Care Med. 2004 Mar;32(3):879-80.

End-of-life planning for the elderly.

Stemp LI.

Publication Types:

Comment

Letter

PMID: 15241133 [PubMed - indexed for MEDLINE]

33: Crit Care Med. 2004 Jul;32(7):1630-1; author reply1631.

Comment on:

Crit Care Med. 2004 Mar;32(3):638-43.

Use of intensive care at the end of life in the United States.

Rady MY.

Publication Types:

Comment

Letter

PMID: 15241131 [PubMed - indexed for MEDLINE]

34: Crit Care Med. 2004 Jul;32(7):1609-11.

Comment on:

Crit Care Med. 2004 Jul;32(7):1484-8.

On speaking less and listening more during end-of-life family conferences.

Meyer EC.

Publication Types:

Comment
Editorial

PMID: 15241113 [PubMed - indexed for MEDLINE]

35: Crit Care Med. 2004 Jul;32(7):1484-8.

Comment in:

Crit Care Med. 2004 Jul;32(7):1609-11.

Family satisfaction with family conferences about end-of-life care in the intensive care unit: increased proportion of family speech is associated with increased satisfaction.

McDonagh JR, Elliott TB, Engelberg RA, Treece PD, Shannon SE, Rubenfeld GD, Patrick DL, Curtis JR.

Department of Medicine, School of Medicine, University of Washington, Seattle, WA, USA.

OBJECTIVE: Family members of critically ill patients report dissatisfaction with family-clinician communication about withdrawing life support, yet limited data exist to guide clinicians in this communication. The hypothesis of this analysis was that increased proportion of family speech during ICU family conferences would be associated with increased family satisfaction. **DESIGN:** Cross-sectional study. **SETTING:** We identified family conferences in intensive care units of four Seattle hospitals during which discussions about withdrawing life support were likely to occur. **PARTICIPANTS:** Participants were 214 family members from 51 different families. There were 36 different physicians leading the conferences, as some physicians led more than one conference. **INTERVENTIONS:** Fifty-one conferences were audiotaped. **MEASUREMENTS:** We measured the duration of time that families and clinicians spoke during the conference. All participants were given a survey assessing satisfaction with communication. **RESULTS:** The mean conference time was 32.0 mins with an sd of 14.8 mins and a range from 7 to 74 mins. On average, family members spoke 29% and clinicians spoke 71% of the time. Increased proportion of family speech was significantly associated with increased family satisfaction with physician communication. Increased proportion of family speech was also associated with decreased family ratings of conflict with the physician. There was no association between the duration of the conference and family satisfaction. **CONCLUSIONS:** This study suggests that allowing family members more opportunity to speak during conferences may improve family satisfaction. Future studies should assess the effect of interventions to increase listening by critical care clinicians on the quality of communication and the family experience.

PMID: 15241092 [PubMed - indexed for MEDLINE]

36: Fam Pract. 2004 Feb;21(1):114.

Comment on:

Fam Pract. 2003 Jun;20(3):276-82.

Palliative care in rural areas.

Seamark DA, Seamark CJ.

Publication Types:

Comment

Letter

PMID: 14760057 [PubMed - indexed for MEDLINE]

37: Home Health Care Serv Q. 2003;23(2):41-53.

Physicians as Medical Center "Extenders" in End-of-Life Care: Physician Home Visits as the Lynch Pin in Creating an End-of-Life Care System.

Cherin DA, Enguidanos SM, Jamison P.

Center for Personal Assistance Services, 3333 California Street, Suite 455, Bakersfield, CA, 93311.

The article reviews a successful community-based end-of-life home care program. Specifically, physician visits were compared in the models of care studied, and it was concluded that the community-based model patients benefited significantly over the standard model of care patients due to the use of physicians.

PMID: 15256350 [PubMed - as supplied by publisher]

38: Home Healthc Nurse. 2004 Apr;22(4):250-5.

Palliative care is more than pain management.

Wheeler MS.

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Publication Types:

Review

Review, Tutorial

PMID: 15073555 [PubMed - indexed for MEDLINE]

39: Int J Gynecol Cancer. 2004 Jul-Aug;14(4):580-8.

Approaches for end-of-life care in the field of gynecologic oncology: an exploratory study.

Ramondetta LM, Tortolero-Luna G, Bodurka DC, Sills D, Basen-Engquist K, Gano J, Levenback C.

Department of Gynecologic Oncology, The University of Texas M. D. Anderson Cancer Center, Houston, TX.

Abstract. Ramondetta LM, Tortolero-Luna G, Bodurka DC, Sills D, Basen-Engquist K, Gano J, Levenback C. Approaches for end-of-life care in the field of gynecologic oncology: an exploratory study. We sought to explore the Society of Gynecologic Oncologists (SGO) members' opinions and decisions about end-of-life issues and incurable conditions. A survey was mailed to members of the SGO. Their responses were recorded on a Likert scale and entered into a database. The survey explored opinions, experiences, and decisions in managing terminally ill gynecologic oncology patients. Of 900 surveys, 327 were returned (response rate, 36%). Seventy-three percent were men, 89% were white, and 72% were of Christian denomination. Respondents believed that 97% of patients who are dying realize that they are dying but stated only 40% of these patients initiate conversations about end-of-life issues. In contrast, 92% of respondents stated that they initiate end-of-life discussions with patients. Ninety-two percent of respondents thought that the patients should be allowed to make end-of-life choices independently after the facts are given to them. However, 44% thought that it is important to influence the way information is presented, and 54% believe that the gynecologic oncologist (GO) controls the outcome of end-of-life discussions. Although the physicians' sex, race, religion, and age did not correlate with their treatment decisions, religion did correlate with less fear of death ($P = 0.011$) and less discomfort when talking with patients about death ($P = 0.005$). Fifty-four percent of respondents believed that the GO controls the outcome of end-of-life discussions, and 40% believe that their actions prolong the process of dying. Expanding our understanding of what motivates GOs to recommend continued treatment over palliation is important for preserving informed patient-motivated end-of-life decisions.

PMID: 15304150 [PubMed - in process]

40: Int J Palliat Nurs. 2004 May;10(5):248; discussion 249-54.

The Assisted Dying for the Terminally Ill Bill.

Joffe L.

House of Lords, London, UK.

PMID: 15228026 [PubMed - indexed for MEDLINE]

41: Int J Palliat Nurs. 2004 May;10(5):244-7.

Is terminal sedation compatible with good nursing care at the end of life?

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Publication Types:

Review

Review, Tutorial

PMID: 15215709 [PubMed - indexed for MEDLINE]

42: Int J Palliat Nurs. 2004 May;10(5):236-41; discussion 242-3.

Voluntary refusal of food and fluids: attitudes of Oregon hospice nurses and social workers.

Harvath TA, Miller LL, Goy E, Jackson A, Delorit M, Ganzini L.

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As the ethical debate about euthanasia and physician-assisted suicide (PAS) continues, one alternative that has been suggested is for the patient to voluntarily refuse all food and fluids (VRFF). The article describes the results of a study of hospice nurses' and social workers' attitudes towards VRFF and compares them with their attitudes towards PAS. In 2001, a questionnaire was posted to nurses and social workers who care for Oregon residents enrolled in hospice programmes to determine their attitudes towards PAS and VRFF. In general, hospice workers expressed support for patients who choose to hasten their death by VRFF; they were less supportive of PAS. The results from this study suggest that perceptions regarding VRFF are significantly different from those regarding PAS. These results may have important clinical implications for nurses and social workers involved in end-of-life care who encounter patients who wish to hasten their deaths.

PMID: 15215708 [PubMed - indexed for MEDLINE]

43: Int J Palliat Nurs. 2004 May;10(5):225-35; discussion 235.

Responding to persistent requests for assistance in dying: a phenomenological inquiry.

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Little is known about how American nurses understand and respond to requests made by decisionally capable patients for assistance in dying. This article is based on a broader qualitative study first reported elsewhere (Schwarz, 2003).

The study used phenomenological interpretation and analysis of stories told by 10 nurses who worked in home hospice, critical care, and HIV/AIDS care settings. Persistent requests for assistance in dying were relatively uncommon, but when heard, participants provided the following responses: refusing assistance, administering palliative drugs that might secondarily hasten dying, tacitly permitting and not interfering with patient or family plans to hasten death, and actively providing direct assistance in dying. Nurses' responses were context-driven; they did not seek guidance from professional codes of ethics or colleagues. Secrecy and collusion were routinely practised. Few participants unequivocally agreed or refused to help patients die; most struggled to find morally and legally acceptable ways to help patients die well. Regardless of how they responded, nurses who believed they had hastened death described feelings of guilt and moral distress. Healthcare professionals who provide care for symptomatic dying patients need opportunities to meet with supportive colleagues, to share the experience of troubling cases and of moral conflict, and to be supported and heard in a 'safe' environment.

PMID: 15215707 [PubMed - indexed for MEDLINE]

44: Int J Palliat Nurs. 2004 May;10(5):218-24; discussion 224.

An interview with Lesley Martin. Interview by Kay Mitchell.

Martin L.

Publication Types:
Interview

PMID: 15215706 [PubMed - indexed for MEDLINE]

45: Int J Palliat Nurs. 2004 May;10(5):215-6.

Ignorance of palliative care clouds the debate.

Coyle N.

Publication Types:
Editorial

PMID: 15215705 [PubMed - indexed for MEDLINE]

46: Int J Palliat Nurs. 2004 May;10(5):214-5.

Euthanasia--mercy or murder.

Mitchell K.

Publication Types:
Editorial

PMID: 15215704 [PubMed - indexed for MEDLINE]

47: Int Urol Nephrol. 2003;35(4):565-8.

Advance care planning in elderly chronic dialysis patients.

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Despite the usefulness of advance directives, most dialysis patients do not complete them. Current views of the advance care planning process emphasize that development of a specific written advance directive is only one small part of the process. Patients and families use advance care planning discussions to plan for death, achieve control over their health care, and strengthen relationships. Studies of chronic dialysis patients have shown that discussions about end-of-life care occur within the patient-family and not the patient-physician relationship. Successful advance care planning requires that dialysis care providers incorporate end-of-life care wishes and palliative care into the overall health care plans for their patients. This review focuses on the past impediments to achieving useful advance directives among dialysis patients and their families and provides some suggestions to improving this important aspect of dialysis patient care.

Publication Types:

Review

Review, Tutorial

PMID: 15198168 [PubMed - indexed for MEDLINE]

48: Intensive Crit Care Nurs. 2004 Aug;20(4):214-22.

An insight into Australian nurses' experience of withdrawal/withholding of treatment in the ICU.

Halcomb E, Daly J, Jackson D, Davidson P.

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Background: The success of biotechnology has created moral and ethical dilemmas concerning end-of-life care in the Intensive Care Unit (ICU). Whilst the competent individual has the right to refuse or embrace treatment, ICU patients are rarely able to exercise this right. Thus, decision-making is left to medical professionals and family/significant others. Aim: This study aimed to explore the lived experience of ICU nurses caring for clients having treatment withdrawn or withheld, and increase awareness and understanding of this experience amongst other health professionals. Methods: Van Manens' (1990) phenomenological framework formed the basis of this study as it provided an in-depth insight into the human experience. A convenience sample of ten ICU Nurses participated in the

study. Conversations were transcribed verbatim and analysed using a process of thematic analysis. Results: Five major themes emerged during the analysis. These were: (1) comfort and care, (2) tension and conflict, (3) do no harm, (4) nurse-family relationships and (5) invisibility of grief and suffering.

Conclusion: The experience of providing care for the adult having treatment withdrawn or withheld in the ICU represents a significant personal and professional struggle. Improvements in communication between health professionals, debriefing and education about the process of withdrawing or withholding treatment would be beneficial to both staff and families and has the potential to improve patient care and reduce burden on nurses.

PMID: 15288875 [PubMed - in process]

49: Intern Med J. 2004 Mar;34(3):139-40; author reply 140-1.

Comment on:

Intern Med J. 2003 Aug;33(8):345-9.

End-stage dementia: why treat at all?

Formby F.

Publication Types:

Comment

Letter

PMID: 15030468 [PubMed - indexed for MEDLINE]

50: J Adv Nurs. 2004 Jun;46(5):558-66.

Haemodialysis patients and end-of-life decisions: a theory of personal preservation.

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BACKGROUND: Lack of knowledge about the end-of-life treatment preferences of patients undergoing haemodialysis is problematic in the acute care setting as, often, patients are unable to communicate their treatment wishes effectively and have not previously documented their desires in the form of advance directives. Existing theoretical models offer an incomplete explanation of end-of-life treatment decisions in haemodialysis patients. **AIM:** This paper reports a study exploring decisions about end-of-life treatment (e.g. cardiopulmonary resuscitation, mechanical ventilation) in people with kidney failure undergoing haemodialysis. **METHODS:** Grounded theory was used. Theoretical sampling led to selection of 20 haemodialysis patients (11 men and nine women with a mean age of 56) who attended three dialysis outpatient centres in central Texas. They were interviewed about end-of-life treatment plans and the use of advance directives (i.e. living wills and durable powers of attorney for health care). Interviews,

transcripts and field notes from the first 12 patients were analysed by making constant comparisons. The remaining eight interviews were used for validation purposes. Data collection and analysis spanned the years 1997-2000. FINDINGS: When prompted to think about and discuss end-of-life treatments, haemodialysis patients chose to focus on living rather than dying. A substantive theory of 'personal preservation' was developed. This consists of three phases: knowing the odds for survival, defining individuality (beating the odds, discovering meaning, being optimistic and having faith in a higher force) and personal preservation (being responsible and taking chances). CONCLUSIONS: The theory of personal preservation furthers understanding of illness behaviour and the process by which patients make decisions about end-of-life treatments. It can be used to sensitize health care professionals to patients' desires and to enhance patient-professional communication.

PMID: 15139945 [PubMed - indexed for MEDLINE]

51: J Am Geriatr Soc. 2004 Jun;52(6):1027-8; author reply 1028.

Comment on:

J Am Geriatr Soc. 2003 Jun;51(6):835-40.

End-of-life care and family involvement.

Iraqi AH, Hughes TL.

Publication Types:

Comment

Letter

PMID: 15161479 [PubMed - indexed for MEDLINE]

52: J Contin Educ Nurs. 2004 May-Jun;35(3):107-20; quiz 141-2.

Learning pain assessment and management: a goal of the End-of-Life Nursing Education Consortium.

Sherman DW, Matzo ML, Paice JA, McLaughlin M, Virani R.

Advanced Practice Palliative Care Master's and Post-Master's Programs, Division of Nursing, New York University, New York, New York 10003-6677, USA.

BACKGROUND: Relief of pain for patients requires that palliative care practitioners have knowledge and skill in both pain assessment and the use of pharmacologic and complementary therapies. METHOD: Pain assessment and management and the teaching strategies suggested within the End-of-Life Nursing Education Consortium curriculum are presented. RESULTS: By addressing the pain experienced by patients with life-limiting illnesses and those at the end of life, the quality of care can be greatly improved. As a multidimensional phenomenon that relates to physical, emotional, and spiritual well-being, the relief of pain enhances the quality of life of patients and lessens the stress experienced by family caregivers. CONCLUSION: The relief of pain and suffering is consistent with the philosophy and goals of nursing as a profession and is a

nursing responsibility.

Publication Types:

Review

Review, Tutorial

PMID: 15195783 [PubMed - indexed for MEDLINE]

53: J Health Econ. 2004 Mar;23(2):217-35.

A longitudinal study of the effects of age and time to death on hospital costs.

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Recent studies indicate that approaching death, rather than age, may be the main demographic driver of health care costs. Using a 29-year longitudinal English dataset, this paper uses more robust methods to examine the effects of age and proximity to death on hospital costs. A random effects panel data two-part model shows that approaching death affects costs up to 15 years prior to death. The large tenfold increase in costs from 5 years prior to death to the last year of life overshadows the 30% increase in costs from age 65 to 85. Hence, expenditure projections must consider remaining life expectancy in the populations.

PMID: 15019753 [PubMed - indexed for MEDLINE]

54: J Interprof Care. 2004 May;18(2):200-1.

Developing methods to improve the quality of end-of-life care.

Hughes R, Addington-Hall J, Aspinall F, Dunckley M, Higginson I.

Department of Palliative Care and Policy, King's College London, London, UK.

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PMID: 15203679 [PubMed - indexed for MEDLINE]

55: J N Y State Nurses Assoc. 2003 Fall-2004 Winter;34(2):22-7.

The New York State Health Care Proxy Law and the issue of artificial hydration and nutrition.

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The New York State Health Care Proxy (HCP) Law allows a surrogate to make medical decisions for an individual when he or she loses the capacity to make

them. In the area of artificial hydration and nutrition, however, this law dictates that if the agent is not aware of the patient's wishes regarding hydration and nutrition, the agent cannot decide about this treatment.

Publication Types:

Case Reports
Review
Review, Tutorial

PMID: 15214290 [PubMed - indexed for MEDLINE]

56: J Natl Cancer Inst Monogr. 2004;(32):119-23.

Treatment of symptom clusters: pain, depression, and fatigue.

Fleishman SB.

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There is not yet sufficient evidence-based experience for the coordinated treatment of three symptoms that cluster in cancer: pain, depression, and fatigue. Each symptom taken individually has accepted treatment modalities. With some overlap between these symptoms, established treatments for one symptom may

"cross-over" and reduce the burden of one, or both of the others. To optimize patient care in advance of the evidence basis, attention to these symptoms is value-added for patients and their families. Standardized screening using the Distress Thermometer for physical, practical, emotional, or spiritual symptoms helps effectively identify patients whose symptoms warrant attention. Cancer Supportive Services, an innovative program at the Continuum Cancer Centers of New York at Beth Israel and St. Luke's-Roosevelt, provides comprehensive intervention throughout the trajectory of care for pain, depression, and fatigue. These services are provided in tandem with efforts to cure or contain the cancer. Cancer Supportive Services sets up a natural entry point to survivors' follow-up or end-of-life care. Such an effort reinforces a basic principle that active symptom management is integral to each patient encounter in the cancer treatment setting.

PMID: 15263052 [PubMed - in process]

57: J Pain Symptom Manage. 2004 Jun;27(6):523-32.

Consideration of hastening death among hospice patients and their families.

Arnold EM, Artin KA, Person JL, Griffith DL.

Department of Psychiatry and Behavioral Medicine, Wake Forest University School of Medicine, Winston-Salem, North Carolina 27157-1087, USA.

The purpose of this study was to describe hospice social workers' perceptions of cases where hospice patients or their family members expressed a desire to

hasten the patient's death. Surveys were mailed to hospice social workers (n=212) in two Southeastern states. Response rate was 36%. Of the 73 respondents, 56.2% had a patient and 26.1% had a patient's family member express a desire to hasten the patient's death. Most patients had a cancer diagnosis (70.4%) and were predominantly male (66.6%), white (94.4%), and were married/had a partner (66.7%). Poor quality of life (28.3%) and concern for suffering (28.3%) were the most common reasons reported for the request to hasten death. These data suggest that the desire for hastened death is not uncommon among hospice patients. Social workers perceive these requests to be related primarily to unmet needs.

Publication Types:

Clinical Trial

Multicenter Study

PMID: 15165650 [PubMed - indexed for MEDLINE]

58: J Pain Symptom Manage. 2004 Jun;27(6):502-12.

What works for therapists conducting family meetings: treatment integrity in family-focused grief therapy during palliative care and bereavement.

Chan EK, O'Neill I, McKenzie M, Love A, Kissane DW.

Center for Palliative Care, Department of Medicine, St. Vincent's Hospital, and Department of Psychiatry, University of Melbourne, Victoria, Australia.

The purpose of this study was to evaluate the treatment integrity of Family-Focused Grief Therapy (FFGT), a preventive intervention designed for families at high risk of poor functioning during palliative care and bereavement. From the 81 families participating in a randomized controlled trial (53 assigned to therapy), 28 were randomly selected for this study of treatment fidelity using the FFGT integrity measure. A total of 109 family sessions were appraised. This represented a review of 62% of treated families, 38% of total therapy sessions, and 87% of the 15 participating therapists. Weighted mean percentage occurrences of therapist behaviors permitted trends in therapy application to be observed. Inter-rater reliability using the FFGT integrity measure was satisfactory, with 88% overall agreement. Eighty-six percent of therapists adhered faithfully to core elements of the model. Therapist competence was evidenced by a strong therapeutic alliance (94%), affirmation of family strengths in over 90%, and focus on agreed themes in 76% of sessions. Therapists averaged 10 grief-related questions per session, 7 on communication-related issues during assessment, 7 on conflict late in therapy, and 4 on cohesiveness across the course of therapy. Consistent application of FFGT, with attention to its four key themes of family communication, cohesiveness, conflict resolution, and shared grief has been demonstrated. The model is generalizable when applied by family therapists.

Publication Types:

Clinical Trial

Randomized Controlled Trial

PMID: 15165648 [PubMed - indexed for MEDLINE]

59: J Pain Symptom Manage. 2004 Jun;27(6):492-501.

Measuring the quality of structure and process in end-of-life care from the bereaved family perspective.

Morita T, Hirai K, Sakaguchi Y, Maeyama E, Tsuneto S, Shima Y; Quality Assurance Committee, Japanese Association of Hospice and Palliative Care Units.

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Measurement of the structure/process of care is the first step in improving end-of-life care. The primary aim of this study was to psychometrically validate an instrument for directly measuring the bereaved family's perception of the necessity for improvement in structural/procedural aspects of palliative care. Different sets of questionnaires were sent to 800 and 425 families who lost family members at one of 70 certified palliative care units in Japan in the development and validation phases, respectively, and 281 families of the latter group in the follow-up phase. The participants were requested to fill out a newly-developed Care Evaluation Scale (CES), along with outcome measures (the perceived experience and satisfaction levels) and potential covariates (the degree of expectation, the Center for Epidemiologic Studies Depression Scale, and the Social Desirability Scale). We obtained 485, 310, and 202 responses in the development, validation, and follow-up phases (response rates: 64%, 75%, and 72%, respectively). The 28-item CES had an overall Cronbach's coefficient alpha of 0.98; the intra-class correlation coefficient in the test-retest examination was 0.57. A confirmatory factor analysis revealed 10 subscales: physical care (by physicians, by nurses), psycho-existential care, help with decision-making (for patients, for family), environment, family burden, cost, availability, and coordination/consistency. The CES subscales were only moderately correlated with the perceived-experience and satisfaction levels of corresponding areas ($r=0.36-0.52$ and $0.39-0.60$, respectively). The CES score was not significantly associated with the degree of expectation, the changes of depression, or the Social Desirability Scale. The CES is a useful tool to measure the bereaved family's perception of the necessity for improvement in structural/procedural aspects of palliative care. The advantages of the CES are: 1) it specifically evaluates the structure and process of care, 2) it directly identifies needed improvements, 3) it is not affected by the degree of expectation, depression, or social desirability, and 4) it has satisfactory psychometric properties.

Publication Types:

Evaluation Studies
Validation Studies

PMID: 15165647 [PubMed - indexed for MEDLINE]

60: J Palliat Med. 2004 Jun;7(3):486-93.

The Balm of Gilead Project: a demonstration project on end-of-life care for safety-net populations.

Kvale EA, Williams BR, Bolden JL, Padgett CG, Bailey FA.

Library Program Office
Office of Information
Veterans Health Administration

Center for Palliative Care, Division of Gerontology and Geriatric Medicine,
University of Alabama at Birmingham, Birmingham, Alabama 35294, USA.

The Balm of Gilead is a comprehensive program of end-of-life care for the populations served by the "safety net" public health system in Alabama's largest county. The Balm of Gilead serves terminally ill persons, predominantly of minority ethnic status who as a group are relatively younger than the national hospice population, and typically lacking in personal financial resources. Care provided by the Balm of Gilead addresses the holistic needs associated with terminal illness in each of its stages and each of its treatment settings. Balm of Gilead professionals and volunteers provide continuity of care across a continuum that includes inpatient palliative care, home hospice services, and specialized palliative care in nursing homes and other community residential settings. Cooper Green Hospital and the Jefferson County Department of Health are principal partners in the program. Community partnerships with local foundations, colleges and universities, faith communities, civic groups, and professional groups complete the collaborative network of the Balm of Gilead Project. This report discusses work to date toward fulfilling the project's two primary objectives: (1) to build the infrastructure necessary to support a comprehensive palliative care program that is available to county residents regardless of their ability to pay and (2) to develop systems and services to foster the institutional and community values that promote excellence in end-of-life care. The Project's current status and future challenges are reviewed.

PMID: 15265364 [PubMed - in process]

61: J Palliat Med. 2004 Apr;7(2):373-9.

The GRACE Project: Guiding End-of-Life Care in Corrections 1998-2001.

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The GRACE (Guiding Responsive Action in Corrections at End of Life) Project promotes the development of end-of-life (EOL) care programs in correctional settings. Managers of pioneer programs were interviewed and worked together with correctional and community professionals in the planning. The project established a resource center, developed and published standards and a handbook, and produced journal articles. Four sites with pioneering programs have undertaken demonstration projects to show how program enhancements could be designed, implemented, monitored, and evaluated. Early data suggest that both frontline staff and supporting organizations have crucial roles to play in sustaining present momentum. When representatives from diverse areas of expertise worked together on this project, innovations emerged that help point the way for future institutional change.

PMID: 15130219 [PubMed - indexed for MEDLINE]

62: J Palliat Med. 2004 Apr;7(2):363-72.

Project ENABLE: a palliative care demonstration project for advanced cancer patients in three settings.

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At the end of the 1990s, based on data from two major studies of end-of-life (EOL) care, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT), and the Hospitalized Elderly Longitudinal Project (HELP), a consensus panel report documented the problems and needs of patients with cancer and other life-limiting diagnoses at end-of-life. A national program of The Robert Wood Johnson Foundation (RWJF), Promoting Excellence in End-of-Life Care, attempted to address these needs by funding demonstration projects to test various approaches to improve identified deficits. In 1998, Project ENABLE (Educate, Nurture, Advise Before Life Ends), one of four RWJF-funded cancer center/hospice collaborations of the Promoting Excellence program, began to address these issues. The jointly sponsored Norris Cotton Cancer Center (NCCC)/Hospice of Vermont and New Hampshire (Hospice VNH) program

provided an integrated approach to the management of life-limiting cancer. Project ENABLE was aimed at alleviating the symptoms of disease and treatment, enhancing clinician and patient/family communication, offering support for families, friends and other caregivers, addressing emotional and spiritual needs of dying people and providing conceptual and administrative structure to provide EOL care consistent with patients' values and preferences. Although patient symptom data is not yet available, other measures of success included improved access to hospice and palliative care services from the time of diagnosis and a sustained palliative care program at two of the three sites in which the program was implemented.

PMID: 15130218 [PubMed - indexed for MEDLINE]

63: J Palliat Med. 2004 Apr;7(2):297-300.

The spirit feather: an ecologically based celebration of life.

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The final moments of a life pose a special and very important time for all participants. Sensitive arrangement of events can provide harmony and a peaceful and memorable transition event. A specific situation, in which a feather is used to symbolize the transition, is reported. Hospice programs can offer ecologically based celebration of life and provide a positive transition for patients, families, friends, and staff.

PMID: 15130207 [PubMed - indexed for MEDLINE]

64: J Palliat Med. 2004 Apr;7(2):279-95.

Palliative educational outcome with implementation of PEACE tool integrated clinical pathway.

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BACKGROUND: House officers frequently lack basic competency in end-of-life care. Few studies have evaluated educational interventions deliberately utilizing physicians' learning strategies, particularly in the context of a concomitant effort at modification of practice patterns. **Study design:** Prospective controlled trial utilizing pre-intervention and post-intervention cross-sectional surveys. **PARTICIPANTS:** Internal medicine residents at a university hospital in their first, second, and third years of training. **Survey:** A 25-item survey modified from previously published instruments. **INTERVENTION:** Residents in the intervention group utilized an experiential learning intervention (integrated, end-of-life clinical pathway: PEACE Tool). The control group delivered care in a standard fashion. **Data analysis:** Survey item and test responses were tabulated and pair-wise comparisons between group means evaluated statistically using two-sample t tests. **RESULTS:** Fifty-four internal medicine residents (n = 24, first-year; n = 17, second-year; and n = 13, third-year) completed the survey. Pre-intervention mean scores on a 16-item knowledge scale were 7.4 (46% correct) for first-year, 8.1 (51%) for second-year, and 9.2 (58%) for third-year residents. Eighteen first-year residents participated in the intervention phase (8 in the intervention, 10 in the control). Mean overall knowledge scores were 46% higher in the intervention group compared to the control group (11.8 versus 8.1 p < 0.001). **CONCLUSIONS:** A time-effective, practice-based strategy led to a significant improvement in knowledge of end-of-life care. Prior to implementation of this strategy competency in end-of-life care was suboptimal among internal medicine residents, in spite of desirable attitudes. Factual knowledge improved slightly with standard, pre-intervention training and experience.

Publication Types:

Clinical Trial

Controlled Clinical Trial

PMID: 15130206 [PubMed - indexed for MEDLINE]

65: J Palliat Med. 2004 Apr;7(2):257-63.

Hydration management at the end of life.

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The management of parenteral hydration at the end of life remains controversial.

The debate centers on whether and/or how often patients should be hydrated, the volume of hydration received, and the benefit versus side effects of parenteral hydration. In order to clarify the routine practice of physicians involved in the end-of-life care in Edmonton, Alberta, Canada, we investigated the routine management of hydration by attending physicians caring for patients dying in a palliative care unit (PCU) at Norwood Capital Care, and in acute care wards at the Royal Alexandra Hospital (RAH) both while receiving and while not receiving consult advice from the Palliative Care Program. We conducted a retrospective chart review of 50 consecutive patients who died in each of the 3 sites included in the study. Data from the last 7 days prior to and including the date of death (day 0) was recorded. The majority of patients at all sites received hydration. The volume of hydration ordered in the Norwood PCU site was significantly different compared to both RAH groups on all days studied ($p < 0.005$). The RAH palliative care group showed a trend for lower hydration volumes compared to the RAH acute care group with significant differences on days 1 and 2 ($p < 0.05$). Throughout the week, for all of the hydrated patients in the Norwood PCU site, hypodermoclysis (HDC) was ordered; for nearly all of the hydrated patients in the RAH acute care group, intravenous (IV) hydration was ordered; and for approximately one third of the hydrated RAH palliative care consult group HDC was ordered, and for the remainder IV hydration was ordered. The RAH acute care group represented the largest percentage of hydrated patients receiving diuretics while the Norwood hospice site represented the lowest. The data raise the possibility that more patients in the RAH acute care group were overhydrated and may have developed symptoms such as edema, ascites, and respiratory distress. This study suggests that hydration at the end of life is managed differently in different settings of care and highlights areas for education to improve management.

PMID: 15130203 [PubMed - indexed for MEDLINE]

66: J Palliat Med. 2004 Apr; 7(2):247-56.

Comment in:

J Palliat Med. 2004 Apr; 7(2): 301-2.

Knowledge, attitudes, and beliefs about end-of-life care among inner-city African Americans and Latinos.

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OBJECTIVE: This project explored end-of-life care preferences and barriers among low-income, urban African Americans and Latino/Hispanic Americans (Latinos) to uncover factors that may influence hospice utilization. **METHODS:** Focus groups were conducted separately for African Americans (4 groups, $n = 26$) and Latinos (4 groups, $n = 27$). Transcripts were coded and analyzed using consensus and triangulation to identify primary themes. **RESULTS:** Four preference themes and four barriers were identified. Results were largely similar across the two groups. Both preferred having families provide care for loved ones but expressed desire to reduce caretaker burden. Groups emphasized spirituality as the primary means of coping and valued the holistic well-being of the patient and family. Barriers reported were closely tied to access to care. Participants reported low

hospice utilization because of lack of awareness of hospice and the prohibitive cost of health care. Latinos were more likely to report language barriers, while African Americans were more likely to report mistrust of the system.
CONCLUSIONS: African Americans and Latinos in this study were highly receptive to end-of-life care that would provide relief for patients and caregivers and emphasize spirituality and family consensus. Improving awareness of hospice services would likely increase utilization.

PMID: 15130202 [PubMed - indexed for MEDLINE]

67: J Palliat Med. 2004 Apr; 7(2): 233-45.

Measuring patient treatment preferences in end-of-life care research: applications for advance care planning interventions and response shift research.

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Understanding the dynamics of patient treatment preferences can be important for end-of-life care research, and has particular salience not only to guide a process of advance care planning (ACP) but also as an outcome measure. Ascertaining the reliability and responsiveness of preferences for life-sustaining treatments within and between patients is a necessary foundation for utilizing patient-agent congruence as an outcome for ACP interventions. This study validated a modified version of the Emanuel and Emanuel Medical Directive for use in both research and clinical applications. Seriously ill patients (n = 168) were asked at baseline and 21 days to consider four common end-of-life health state scenarios, to indicate their goals for treatment, and to state their preferences for six specific treatments. We investigated the reliability and validity of this tool. We found that preferences for life-sustaining treatments were highly intercorrelated, and internally consistent across treatments by scenario and across scenarios by treatment. Preferences for pain medications were, however, distinct from preferences for other treatments. Preference scores exhibited stability over follow-up, and demonstrated both concurrent and discriminant validity. We detected a small effect size for change in preferences as a function of health state change, suggesting that re-prioritization response shifts do occur but are small in magnitude in these patient samples over this time frame. We conclude that this measure is reliable and valid for use in clinical settings and for evaluating interventions designed to improve patient-agent congruence about patient preferences for life-sustaining treatments. Clinical applications of the tool are discussed.

Publication Types:
Validation Studies

PMID: 15130201 [PubMed - indexed for MEDLINE]

68: J Palliat Med. 2004 Apr; 7(2): 221-32.

End-of-life care in nursing homes: residents in hospice compared to other end-stage residents.

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OBJECTIVE: To compare residents in hospice care at admission to the nursing facility to end stage residents not in hospice at admission. **DESIGN AND METHODS:** We analyzed 18,211 admission assessments recorded in the Minimum Data Set (MDS)

during the year 2000 throughout the United States for residents classified as having an end-stage disease (6 or fewer months to live). Fifty-nine percent (n = 10,656) of these residents were in hospice care at the time of their admission assessment. We used these MDS admission assessments to compare residents in hospice care to other end-stage residents not in hospice for demographic characteristics, health status, and treatments. **RESULTS:** Hospice residents at admission were significantly more likely to be female, older, white, and widowed than other end-stage residents at admission. There were significant differences between hospice residents and other residents at end stage in the use of advanced directives at admission. Hospice residents at admission experienced significantly more frequent and more intense pain than other end-stage residents at admission, while these hospice residents also showed greater impairment in cognitive ability and physical function. While cancer was the most common disease among these end-stage residents, it was significantly more prevalent among hospice residents. **IMPLICATIONS:** Many end-stage residents may not be receiving adequate palliative care in nursing facilities; further study of this is warranted. The MDS should be revised to record minimum standards for palliative care with or without the use of hospice to improve end-of life care in nursing facilities.

PMID: 15130200 [PubMed - indexed for MEDLINE]

69: J Pract Nurs. 2004 Spring;54(1):12-3.

A person's right to active or passive euthanasia.

Leonard C, Morris M, Veney J.

PMID: 15193014 [PubMed - indexed for MEDLINE]

70: J Psychosom Res. 2003 Nov;55(5):445-51.

The hospice patient's primary caregiver. What is their quality of life?

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OBJECTIVE: The purpose of this study was to (1) assess the quality of life (QOL)

of the primary caregivers of hospice patients and (2) to analyze the ability of the hospice staff to accurately judge caregiver QOL. METHODS: A longitudinal pilot study of QOL of caregivers of patients entering hospice was undertaken. Caregivers and hospice personnel completed numerous questionnaires every 2 weeks until patient death. Global QOL and component constructs, as well as the demands of illness on the caregiver and profile of moods, were assessed. Simple descriptive statistics at each time point and summary measures (area under the curve) were calculated to describe the QOL profile of caregivers and staff perceptions of the caregivers. Cronbach's alpha coefficient was applied to verify tool internal consistency in a hospice population. Correlation coefficients were supplemented by Bland-Altman procedures for comparing scales measuring the same construct to compare the scores given by caregivers about themselves and staff ratings of the caregivers. The study had 80% power to detect an intraclass difference between caregiver and staff ratings of the caregiver of 0.4 times the standard deviation using a two-sided paired t test with a 5% type I error rate. RESULTS: Caregiver QOL was relatively high and stable over time. Caregiver's QOL was correlated with the patient's overall QOL/hospice staff accurately evaluated caregiver QOL. CONCLUSIONS: By drawing attention to issues that affect the caregiver, we can improve delivery of hospice care and positively impact QOL for both caregiver and patient. Linear analog self-assessment scales are valuable tools for hospice staff to assess caregivers.

PMID: 14581099 [PubMed - indexed for MEDLINE]

71: JONAS Healthc Law Ethics Regul. 2004 Jan-Mar;6(1):1-2; author reply 2.

Do-not-resuscitate (DNR).

Murphy TF.

Publication Types:
Letter

PMID: 15206170 [PubMed - indexed for MEDLINE]

72: Lippincotts Case Manag. 2004 Jul-Aug;9(4):166-174.

Enhancing the Role of Case Managers With Specialty Populations: Development and Evaluation of a Palliative Care Education Program.

Howell D, Prestwich C, Laughlin E, Giga N.

Doris Howell, PhD, RN, is chair, Oncology Nursing Education and Research, University Health Network, Toronto, Ontario. At the time of the case management education program development was practice development consultant with the HPCNet project. Has been in cancer care for over 25 years in various roles. Dissertation work focused on home care utilization and place of death for cancer patients.; Catherine Prestwich, BScN, RN, is a graduate of Queen's University School of Nursing. Her involvement in palliative care has been integral to the development and implementation of the Hospice Palliative Care Network in Toronto since 1999. She is an expert in palliative care as a palliative care coordinator

consultant at the Toronto Community Care Access Centre.; Emmy Laughlin, BScN, RN, is a graduate from Ryerson University School of Nursing. Bringing over 30 years of hospital nursing experience, she has worked in the home care field, specializing in palliative care for the past 10 years, and is currently employed in the Hospice Palliative Care Network as a care coordinator consultant.; Nasreen Giga, BScN, RN, is a graduate from Ryerson University School of Nursing and presently a care consultant in Hospice Palliative Care Network. She has expertise in community and hospital-based palliative care with a special focus on end-of-life care in diverse cultural populations. Her focus is on advancing the ethical principles of palliative care on resource allocation roles of care coordinators.

Palliative home care is an important component of the care system for patients at the end of life and case management is considered an essential element of the Canadian home care system. Case managers play a critical role in allocating resources, thus influencing the costs and the viability of palliative home care. Case management education programs focused on care coordination with specialty palliative care populations are nonexistent. An education program targeted at improving the knowledge and skills of case managers in allocating resources to palliative care populations was developed and pilot-tested in a metropolitan Canadian city home care program. Core curriculum was based on an initial learning needs assessment and used case-based problem solving to enhance case-management skills. An improvement in knowledge was noted on posttests and case managers described increased comfort and confidence in their role as case managers to this patient population. Home care organizations caring for palliative care populations must ensure case managers are prepared for case management roles with specialty populations if the home is to be rendered an appropriate and viable care setting for patients at the end of life.

PMID: 15273601 [PubMed - as supplied by publisher]

73: N Engl J Med. 2004 Aug 5;351(6):611-2; author reply 611-2.

Comment on:

N Engl J Med. 2004 May 13;350(20):2029-32.

Dying and decision making.

Angelotti M, Barolet LR.

Publication Types:

Comment
Letter

PMID: 15295058 [PubMed - indexed for MEDLINE]

74: N Z Med J. 2004 Jun 18;117(1196):U935.

Caring for patients and families at the end of life: withdrawal of intensive care in the patient's home.

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AIM: To describe our experience of transporting 17 intensive care patients home to die. DESIGN: A brief report. SETTING: Mixed medical/surgical intensive care unit (ICU). RESULTS: After discussions with their families, 17 adult patients in whom ongoing care was deemed either inappropriate or futile were transported home. Once there, intensive care modalities of ventilation and vasopressor therapy were withdrawn. The patients were sedated initially with intravenous morphine and if death was not immediately imminent, subcutaneous morphine was administered. In these cases where death took longer than 2 hours, the patients were managed with the assistance of district nurses, the family general practitioner, or staff from the South Auckland Hospice. CONCLUSIONS: All the patients in this report were Maori or Polynesian and all families reported this as a positive experience. Since completion of this report, we have taken our first European patient home to die.

PMID: 15280939 [PubMed - indexed for MEDLINE]

75: N Z Med J. 2004 Jun 18;117(1196):U934.

End of life decision-making by New Zealand general practitioners: a national survey.

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AIM: To explore type and incidence of medical decisions at the end of life that hasten death made by general practitioners in New Zealand, within the context of access to palliative care. METHOD: An anonymous questionnaire investigating the last death attended in the previous 12 months was sent to 2602 general practitioners (GPs) in New Zealand. RESULTS: From a 48% (1255) response, 88.9% (1116) GPs indicated access to an interdisciplinary pain management or palliative care team. Of those attending a death in the previous 12 months, 63% (693) had made a prior medical decision. These decisions included withdrawing/withholding treatment or increasing pain relief with (a) probability death would be hastened 61.8% (428) or (b) partly or explicitly to hasten death 32.6% (226). Moreover, death was caused by a drug supplied or administered by the GP in 5.6% cases (39), actions consistent with physician-assisted death. CONCLUSION: Physician-assisted death provided by some general practitioners in New Zealand is occurring within the context of available palliative care.

PMID: 15280938 [PubMed - indexed for MEDLINE]

76: Niger Postgrad Med J. 2004 Mar;11(1):64-7.

Care for the terminally ill: a review of deaths in the gynaecological wards of a tertiary institution, 1986-2000.

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BACKGROUND: There is yet no formula to predict the expected date of death, however this information may be invaluable to the terminally ill, care givers, friends and family members to write the will, arrange for end-of-life care, settle disputes, and to make plans for burial ceremonies. **OBJECTIVE:** The study is an audit of all deaths in the gynaecological wards to determine the causes of death and highlight the care option for the terminally ill patient. **STUDY METHODS:** The admission ward registers and the duplicate copies of issued death certificates between 1986-2000 were studied. Details of the individual patients diagnosis and at death or discharge were collected and crosschecked with the patient's casenote. The collected data was subjected to statistical analysis using appropriate computer software. **RESULTS:** A total of 10,485 admissions were recorded in the study period. There were 89 (0.85%) deaths and 27(0.26%) discharges against medical advice. The yearly rate of death varied between 0.36% and 1.66% admissions. Patients' discharging themselves from the gynaecological wards against medical advice started in 1992, and was at a maximum (2.0%) in 1996. Carcinoma of the cervix (30.3%) was the most frequent cause of death next was ovarian cancer (29.2%). Death following complications from criminal abortions (11.2%) was fourth while deaths subsequent to operation for uterine fibroids and ectopic pregnancies were 2.2% each. Patients dying from complication of abortion were the youngest (22.6 years +/- 9.13), while patients dying from endometrial carcinoma were the oldest (64.75 years +/- 9.84). The mean age of patients dying from advance gynaecological malignancies was 44.13 years +/- 17.07, which is significantly higher than the mean age of patients dying from complications of abortion, $P < 0.00015$ (Student's T-Test, two tail, type 2). **CONCLUSION:** Advanced malignancies of the cervix, ovary and chorion carcinoma are the major causes of gynaecological deaths. Next, are deaths resulting from the complication of criminal abortion. Patients' discharge against medical advice as option of care needs further investigation.

PMID: 15254575 [PubMed - in process]

77: Nurs Outlook. 2004 May-Jun;52(3):118-25.

Effects of end-of-life discussions on patients' affective outcomes.

Song MK.

University of Wisconsin School of Nursing, k6/323 Clinical Science Center, 600 Highland Avenue, Madison, WI 53792-2455, USA. mksong@wisc.edu

Publication Types:

Review

Review, Tutorial

PMID: 15197360 [PubMed - indexed for MEDLINE]

78: Nurs Times. 2004 Jun 1-7;100(22):70-1.

Supporting colleagues when patients die. Interview by Janis Smy.

Bennett E.

Publication Types:
Interview

PMID: 15195550 [PubMed - indexed for MEDLINE]

79: Nurs Times. 2004 Jun 1-7;100(22):26-7.

'Caring for a patient with cancer was a turning point'.

Baron S.

Publication Types:
Case Reports

PMID: 15195539 [PubMed - indexed for MEDLINE]

80: Nurs Times. 2004 Jun 1-7;100(22):20-3.

Cancer care.

White A.

PMID: 15195537 [PubMed - indexed for MEDLINE]

81: Nursing. 2004 Apr;34(4):50-1.

Comment in:
Nursing. 2004 Jul;34(7):10.

Healing the mind and spirit as the body fails.

Furman J.

PMID: 15247675 [PubMed - indexed for MEDLINE]

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

Surviving the stresses of clinical oncology by improving communication.

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

PMID: 15065704 [PubMed - indexed for MEDLINE]

83: *Origins*. 2004 Apr 8;33(43):748-51.

On withdrawing medically administered nutrition and hydration.

Harvey J, Hamel R.

Georgetown University Center for Clinical Bioethics, Washington, DC, USA.

Publication Types:
Addresses

PMID: 15139354 [PubMed - indexed for MEDLINE]

84: *Origins*. 2004 Apr 8;33(43):744-8.

Should nutrition and hydration be considered medical therapy?

McMahon K.

St. Charles Borromeo Seminary, Overbrook, PA, USA.

Publication Types:
Addresses

PMID: 15139353 [PubMed - indexed for MEDLINE]

85: *Origins*. 2004 Apr 8;33(43):741-4.

Nutrition and hydration: patients in a persistent vegetative state.

Diamond E.

Linacre Institute, Catholic Medical Association, USA.

Publication Types:
Addresses

PMID: 15139352 [PubMed - indexed for MEDLINE]

86: Origins. 2004 Apr 8;33(43):737, 739-40.

Care for patients in a "permanent" vegetative state.

Pope John Paul II.

Publication Types:
Addresses

PMID: 15139351 [PubMed - indexed for MEDLINE]

87: Palliat Med. 2004 Apr;18(3):202-16.

The quality of medical care at the end-of-life in the USA: existing barriers and examples of process and outcome measures.

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CONTEXT: Cancer is a leading cause of morbidity and mortality in the USA and despite many recent advances in detection and treatment, over half a million cancer patients in this country will die from their disease each year.

OBJECTIVE: Using cancer as a prototype, we provide a conceptual framework to identify and review barriers to optimal end-of-life care and propose examples of linked process and outcome measures that could be used to evaluate whether standards of optimal end-of-life care are being achieved. METHODS: We propose a conceptual model of end-of-life care and use this model to review the published literature to identify the key goals of optimal end-of-life care and summarize existing barriers to optimal end-of-life care. We then provide examples of process and outcome measures linked to the goals of optimal end-of-life care and domains within the conceptual framework. RESULTS: Within all components of care at the end-of-life--societal attitudes, health care system(s), providers, and patients and their families--there are significant barriers to the quality of care. Some of the most critical barriers to optimal care at the end-of-life in the USA are limited availability, and coverage of, co-ordinated service delivery; poor provider communication and diagnostic skills; limited opportunities for training in palliative care; patient fears and attitudes towards the sick role, and a lack of, or inadequate health insurance. Proposed patient, provider, and system level measures of the quality of care were guided by goals of optimal end-of-life care, and focus on communication about prognosis

and risks and benefits of treatment, development of clear and informed treatment goals, delivery of services consistent with treatment goals, and promotion of quality of life. CONCLUSIONS: At present, there are substantial societal, health care system, provider, and patient barriers to obtaining optimal cancer care at the end-of-life. Ongoing discussions about appropriate measures of the quality of end-of-life care are gaining momentum, however. The proposed process and outcome measures for assessing optimal end-of-life care use cancer as a prototype, but are broadly applicable to other patient populations with life-threatening disease.

PMID: 15198133 [PubMed - indexed for MEDLINE]

88: Palliat Med. 2004 Apr;18(3):184-94.

Delirium in advanced cancer patients.

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Delirium in advanced cancer is often poorly identified and inappropriately managed. It is one of the most common causes for admission to clinical institutions and is the most frequently cited psychiatric disorder in terminal cancer. Diagnosis of delirium is defined as a disturbance of consciousness and attention with a change in cognition and/or perception. In addition, it develops suddenly and follows a fluctuating course and it is related to other causes, such as cancer, metabolic disorders or the effects of drugs. Delirium occurs in 26% to 44% of cancer patients admitted to hospital or hospice. Of all advanced cancer patients, over 80% eventually experience delirium in their final days. In advanced cancer, delirium is a multifactorial syndrome where opioids factor in almost 60% of episodes. Delirium in such patients, excluding terminal delirium, may be reversible in 50% of cases. Providing adequate end-of-life care for a patient with delirium is the main challenge. The family needs advice and it is important to create a relaxing environment for the patient. The primary therapeutic approach is to identify the reversible causes of delirium. Some therapeutic strategies have been shown to be effective: reduction or withdrawal of the psychoactive medication, opioid rotation, and hydration. Haloperidol is the most frequently used drug, and new neuroleptics such as risperidone or olanzapine are being tested with good results. Methylphenidate has been used for hypoactive delirium.

Publication Types:

Review

Review, Tutorial

PMID: 15198131 [PubMed - indexed for MEDLINE]

89: Qual Health Res. 2004 Jul;14(6):816-35.

Palliative care, care for life: a study of the specificity of residential palliative care.

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In this study, the authors describe the concept of palliative care as applied in a palliative care unit. They conducted in-depth interviews with 8 patients, 9 relatives, and 24 caregivers from two residential palliative care units. Observation of the care and of team meetings and analysis of patient records provided additional data. Palliative care involves a specific concept of care, the central focus of which is life. This is realized by two strategies. The first is to create space to live by diverting attention from the sick body, moving the illness into the background. The second is to fill the space as meaningfully as possible, so that patients can enjoy life even in the face of death. The quality of the caregiving process in palliative care is determined by a range of conditions and processes that reflect its complexity.

PMID: 15200802 [PubMed - indexed for MEDLINE]

90: Respir Med. 2004 May;98(5):439-45.

The last year of life of COPD: a qualitative study of symptoms and services.

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INTRODUCTION: To assess the symptoms experienced and their impact on patients' lives in the last year of life of COPD, and to assess patients' access to and contact with health services. **METHOD:** Qualitative analysis using the framework approach of in-depth interviews with 25 carers of COPD patients who had died in the preceding 3-10 months. **RESULTS:** The average age of death was 77.4 years. The majority of patients died in hospital. The major symptom reported by the carers was breathlessness which impaired the deceased's mobility and contributed to their being housebound. Anxiety and panic were also associated with breathlessness. Depression was reported. Oxygen, though beneficial, was seen to impose lifestyle restrictions due to increasing dependence on it. Some patients only health care contact was through repeat prescriptions from their GP whereas three had regular follow up by a respiratory nurse specialist who linked community and secondary care. Overall, follow-up, systematic review or structured care were uncommon. **DISCUSSION:** Breathlessness causes major disability to patients with COPD in the last year of life. The expertise of palliative care in treating breathlessness may be valuable in these patients many of whom lacked regular health service contact in the year before death. Patients who are housebound with high levels of morbidity require community health services. Respiratory nurse specialists were rarely involved in the patients' care and may provide a link between the GP, the chest physician and the palliative care team.

PMID: 15139573 [PubMed - indexed for MEDLINE]

91: RN. 2004 May;67(5):59-62.

Advance directives: your role.

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PMID: 15199648 [PubMed - indexed for MEDLINE]

92: Soc Sci Med. 2004 Jul;59(1):57-68.

Planning for the end of life: the views of older people about advance care statements.

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Advance statements about medical care have been heralded by some as a solution to the problem of end of life decision making for people not able to participate in discussions about their care. Since death is now most likely to occur at the end of a long life, it is important to understand the views and values which older people express in relation to these. This paper reports on a study which used focus groups to explore older people's views about advance statements and the role these might play in end of life care decisions. Participants were 32 older people or their representatives who belonged to six diverse community groups in Sheffield, UK. Advance statements were understood primarily in terms of their potential to aid personal integrity and to help the families of older people by reducing the perceived 'burden' of their decision making. However, concerns were expressed about the perceived link between advance care statements and euthanasia, their future applicability, and the possibility that preferences for care may change. Participants also reported worries and difficulties related to thinking about and discussing death and dying. Trust between doctor and patient, built up over time, was perceived to be important in creating an environment in which the communication necessary to underpin advance care planning could take place. Lastly, participants did not perceive that during dying they would be ready necessarily to adhere to an advance statement and 'disengage' from their lives. We conclude that, rather than emphasising the completion of advance statements, it may be preferable to conceptualise advance care planning as a process of discussion and review between clinicians, patients and families. Copyright 2003 Elsevier Ltd.

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93: Soc Sci Med. 2004 Jun;58(12):2571-83.

"Symbiotic niceness": constructing a therapeutic relationship in psychosocial

palliative care.

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The concept of symbiotic niceness illustrates a mutually shared advantage in the nurse-patient relationship. This relationship is premised on the co-production of niceness through the doing of psychosocial care. This paper presents an account of 'symbiotic niceness' produced in palliative care nurses' talk. The data are collected from two hospices and one general hospital for the dying. The analysis of talk demonstrates how psychosocial care can be understood as the collaborative practice of 'niceness' in the daily activities of participants, and how they collaboratively achieve reciprocal and therapeutic relevance for their talk. Participants co-engage in a 'selling game'. Through the activities of selling, a set of personal assets that constitute their personal Curriculum Vitae (CV) are revealed. It suggests that nurses' assets, when combined with patients' assets, function as marketable 'products' to produce an impression of nice patients and professionals. This in turn leads to the production of an impression of 'nice' organisations. Impression management is presented as a key strategy for the production of marketable niceness. Through the co-performance of niceness in talk, both nurses and patients are constructed as people who are somewhat charismatic, friendly, informal, understanding and concerned. This paper argues that underpinning the co-enactment of symbiotic niceness is the sharedness of patients' and nurses' experiences and a reciprocal notion of therapeutic help. It serves as a means of managing relations between palliative care nurses and dying patients. Symbiotic niceness thus represents a core component of professional and patient identity which works to maintain social orderliness as well as to advance personal, professional and organisational aspirations.

PMID: 15081206 [PubMed - indexed for MEDLINE]

94: Soc Sci Med. 2004 Jun;58(12):2431-44.

Place of death: preferences among cancer patients and their carers.

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The place of death of cancer patients has become an important theme in UK cancer and palliative care policy. This paper examines the place of death preferences of 41 terminally ill cancer patients and 18 of their informal carers, living in the Morecambe Bay area of north-west England. We interviewed cancer patients referred to the research team by 13 specialist palliative care professionals; patients had an estimated 3 months of life remaining. The study design involved an in-depth qualitative interview with each patient soon after referral to the study, followed by an interview some 4 weeks later and subsequent tracking interviews by telephone at 2-4 week intervals until death occurred. Interviews were also conducted with main coresident carers soon after patient referral to the study and again in the post-bereavement period. Thirteen factors were

identified as shaping the place of death preference of patients and carers. These are organised into four thematic domains: the informal care resource, management of the body, experience of services, and existential perspectives. In documenting these factors, this paper adds significantly to current knowledge on the factors that shape place of death preference, a field of enquiry acknowledged to be underdeveloped (J. Palliative Med. 3 (2000) 287). More importantly, it uncovers some of the reasons that underpin these preferences. Our research revealed a much stronger preference for deaths in a hospice than had been anticipated, leading us to take a qualified stance on the current policy drive in favour of home deaths by those charged with delivering UK cancer and palliative care services.

PMID: 15081195 [PubMed - indexed for MEDLINE]

95: Soc Work. 2004 Jul;49(3):432-40.

Validation of the health care surrogate preferences scale.

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Recent advances in health care technology have increased the number of health care decisions made by acute care patients and those who act on their behalf, known as health care surrogates. This study reports on the validation of a new measure, the Health Care Surrogate Preferences Scale. Designed to assess the willingness of adults to perform and convey the duties required to communicate patient preferences, the scale offers a promising tool for use by social workers in health care settings. Development, evaluation, application of the new measure, and future research needs are discussed.

Publication Types:
Validation Studies

PMID: 15281698 [PubMed - indexed for MEDLINE]

96: Spec Law Dig Health Care Law. 2003 Sep;(293):9-20.

Advocacy for social change: improving care and expanding options at the end of life.

Tucker KL.

Publication Types:
Legal Cases

PMID: 15222179 [PubMed - indexed for MEDLINE]

97: Support Care Cancer. 2004 Mar;12(3):168-75.

Support group programme for relatives of terminally ill cancer patients.

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GOALS: In order to improve the support for family of terminally ill patients who cared for a dying relative at home, a project with a group programme was started. This article is an evaluation of the programme. The aims of this study were to describe the opinions of participants in a support group programme about the programme and how they felt they had benefited from it. **PATIENTS AND METHODS:** All subjects (n=39) who completed the programme answered five open-ended questions, and 12 of them were interviewed in semi-structured interviews that were analysed using the phenomenographic method. **RESULTS:** Three main categories were identified in the interviews: (1) Practical condition and external circumstance--which condition had to be met for participation in the programme. (2) Group effects--the subjects felt that the programme was helpful in several respects, they perceived the programme being an important complement to the palliative home care, they benefited from mutual experiences shared among group members, the programme was also beneficial to the patients and was perceived to have had a health-promoting effect on the relatives. (3) The disease--the issue of how much the patients disease affecting the relatives situation were raised in the groups. **CONCLUSION:** The results showed the value of the programme for relatives of terminally ill patients nursed in their home. The subjects emphasised the importance of the opportunity to meet people who are in a similar situation.

Publication Types:
Evaluation Studies

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98: Support Care Cancer. 2004 Feb;12(2):86-90. Epub 2003 Dec 18.

Principles of medical ethics in supportive care: a reflection.

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The possibility of medical-moral controversy in contemporary health care delivery is occasioned by the interfacing of expanding technology with both professional and personal value systems, frequent and significant knowledge deficits on the part of health care consumers, and increased circumspection of and economic constraints experienced by health care providers. Particularly in an era of increasing regulatory mandates and the frequent and lamentable decrease in the availability of human, natural, and institutional resources, an understanding of the function of ethical analysis is indigenous to care, which is simultaneously medically appropriate and morally indicated. But while a familiarity with and an appreciation of the potential contribution of ethical reasoning is essential in all health care delivery, it assumes critical

importance in supportive care. In that venue, where the rigors and demands of aggressively therapeutic interventions have ceased and the goal and the demeanor of care have shifted to the palliative mode, heightened attention to the principles of medical ethics is necessary for the balancing of rights and responsibilities for health care consumers and providers alike. This issue ultimately can be singularly salient in providing care that is patient centered and directed. Individuals acting as moral agents, suggesting what "ought" to be done in a given situation, either for themselves or as they are involved in rendering or supporting decisions proffered for or by other moral agents, particularly those in extremis, those in the throes of terminal illness following the collapse of the curative mode, need recourse to principles to facilitate their reasoning. Although the employment of each principle of medical ethics offers guidelines for reflection on the most comprehensive and appropriate care, it is attention to autonomy, informed consent, and beneficence that promotes the most effective supportive care. For even as the question of medical viability is settled in favor of palliation over aggression, there remain the entanglements of psychological stability, conflicting value systems, and the impact of the social milieu as well as the issues of economic responsibility and resource accountability. It is in the attention to the medical ethical principles of autonomy and informed consent, especially as amplified by the creation of and respect for advance directives, that the most holistic and productive supportive care can be offered. It is also in this posture that appeal to the principle of beneficence is made. Just as the progress of disease and, therefore, the realistic goals of care change, so too can an individual's considered opinion with regard to end-of-life decisions. Preserving the integrity of patients and caregivers alike and engaging in fruitful and informative dialog prior to seeking volitional authorization or operationalizing a supportive approach demonstrates renewed concern for both patient autonomy and professional accountability in the provision of a comprehensive end-of-life care plan. Discussions will not be avoided until they can no longer effectively take place, salient questions will not go unanswered, and decisions around end-of-life questions, in the mode of supportive care, will not be absent where care was exercised to engage patients in significant dialog earlier rather than later in their disease processes.

Publication Types:

Review

Review, Tutorial

PMID: 14685834 [PubMed - indexed for MEDLINE]

99: Support Care Cancer. 2004 Feb;12(2):132-6. Epub 2003 Nov 20.

Attitudes to terminal patients' unorthodox therapy: Finnish doctors' responses to a case scenario.

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We carried out a postal survey of a sample of Finnish doctors (n=1182) concerning their attitudes and ethical decisions in end-of-life care. A scenario was presented in which a patient with terminal cancer wished to obtain

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unorthodox treatment. Factors possibly influencing decision making such as general attitudes, life values and demographics were investigated. The response rate was 62%. The patient's plan to use unorthodox treatment was accepted by 54% of doctors. Gender or speciality did not influence the decision, but doctor's age was a significant factor ($P=0.0005$). Doctors aged 35-49 years were more accepting; younger and older ones less accepting. Doctors who had clinical experience in terminal care were more compliant to the patient's plan ($P=0.034$). A stepwise logistic regression analysis was used to create a model for explaining not accepting versus accepting the treatment with the background variables. Altogether eight independent significant variables were included in the final model of explaining a doctor's choice in the presented scenario. According to the model the patient's wish was more frequently accepted if the doctor was middle-aged, had clinical experience in terminal care, valued a high standard of living, considered terminal care satisfying, was less critical of health economics, considered advance directives helpful, had a high fear-of-death index score, and valued professional status less.

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