EthxWeb Search Results

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Document 1
Stiefelhagen, Peter
[Treatment limits at the end of life: what is legally protected, what is ethically acceptable?]. = Therapiebegrenzung am Lebensende: Was ist rechtlich abgesichert, was ethisch vertretbar?
MMW Fortschritte der Medizin 2011 Nov 24; 153(47): 18
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Document 2
Wiese, C H R; Duttge, G; Taghavi, M; Lassen, C L; Meyer, N; Andreesen, R; Graf, B M; Pfistinger, J
Deutsche medizinische Wochenschrift (1946) 2011 Nov; 136(45): 2302-7
Abstract: General out-patient palliative care (GOPC) must be integrated into the care of patients with life-limiting diseases. Aim of the study was to evaluate experiences of general practitioners concerning advance directives and palliative emergency sheets.
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Document 3
Dyer, Clare
Legalisation of assisted dying does not harm palliative care, study concludes.
BMJ (Clinical research ed.) 2011 October 24; 343: d6779
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Document 4
Nicholas, Lauren Hersch; Langa, Kenneth M; Iwashyna, Theodore J; Weir, David R
Regional variation in the association between advance directives and end-of-life Medicare expenditures.
Abstract: It is unclear if advance directives (living wills) are associated with end-of-life expenditures and treatments.
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Document 5
Just because I'm old!
Pesut, Barbara; Bottorff, Joan L; Robinson, Carole A

Be known, be available, be mutual: a qualitative ethical analysis of social values in rural palliative care.

BMC medical ethics 2011 September 28; 12: 19

**Abstract:** Although attention to healthcare ethics in rural areas has increased, specific focus on rural palliative care is still largely under-studied and under-theorized. The purpose of this study was to gain a deeper understanding of the values informing good palliative care from rural individuals' perspectives.

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de la Brière, Alice; Tocheport, Pascale

[Changing the collective impression of palliative care]. = Soins palliatifs, évolution de la représentation collective.

Soins; la revue de référence infirmière 2011 Sep(758): 34-7

**Abstract:** The general public and health professionals may have a mistaken impression of palliative care and the Leonetti law. Thanks to training and information on the measures taken by the government with regard to the development of palliative care, the palliative culture is gradually becoming integrated into healthcare structures and mentalities.

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Nectoux, Martine

[The National Observatory on End of Life Care, progress for palliative care]. = L'Observatoire national de la fin de vie, une avancée pour les soins palliatifs.

Soins; la revue de référence infirmière 2011 Sep(758): 50-1

**Abstract:** Created in 2010, the French National Observatory on End of Life Care is responsible for drawing up an overview of existing knowledge in order to gain a better understanding of the conditions of end of life. It must contribute to the dissemination of the palliative culture and the development of training and research. Its work must also throw light on the choices made in the area of health policies. Nursing expertise is therefore crucial to the fulfilment of these objectives.

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Mitchell, John J Jr.

The findings of the Dartmouth Atlas Project: a challenge to clinical and ethical excellence in end-of-life care.

The Journal of clinical ethics 2011 Fall; 22(3): 267-76

**Abstract:** The Dartmouth Institute for Health Policy and Clinical Practice Atlas Project found "staggering variations" in the quality and quantity of end-of-life care provided to Medicare patients with severe chronic illness across the United States. Particularly concerning is the finding that more care is provided to patients who live in "high-supply" areas, irrespective of the effectiveness of care, and that more care often equaled inappropriate care that increased patients' suffering at the end of life. Patients in "lower supply" areas typically received better, more appropriate levels of care and reported higher levels of satisfaction with the care they received.
Manzini, Jorge L
**Palliative sedation: ethical perspectives from Latin America in comparison with European recommendations.**
Current opinion in supportive and palliative care 2011 Sep; 5(3): 279-84

**Abstract:** Palliative sedation is a standard procedure used in palliative care especially for patients at the very end of their lives, who are enduring otherwise intractable suffering. It consists of the administration of sedatives and, when necessary, other drugs, usually by infusion, either subcutaneously or intravenously, at the necessary rate to achieve the patient's relief, by means of reducing the consciousess of the patient. If this administration is not discontinued, the usual outcome is the patient's death. So, the most frequent criticisms regarding the procedure are those that consider it as a form of euthanasia. The intention of the review is to analyze the status of the question in Europe and Latin America.

Cerminara, Kathy L
**The law and its interaction with medical ethics in end-of-life decision making.**
Chest 2011 Sep; 140(3): 775-80

**Abstract:** The previous two articles in this series explored the historical and theoretical development of medical decision making from initial reliance on medical beneficence to a more recent emphasis on patient autonomy. The law of withholding and withdrawal of treatment has much in common with medical ethics. It is based on concerns about patient autonomy expressed by courts, legislatures, and the executive branch of the government. Legally, the patient's right of self-determination has been based on a variety of sources ranging from state and federal constitutions to the common law of torts and from cases to statutes and regulations. Understanding the various sources of the law, the distinctions among those sources, and the interaction of the branches of government in this context assists in understanding the law itself. In our federalist system of government, significant legal variations can exist among the states, but although technically valid, excessive concern about compliance with the precise contours of each state's statute when surrogate decision makers are engaging in bedside deliberations is unnecessary. Regardless of source or precise legal contours, the overall goal, which neither the physician nor the patient's surrogate or proxy decision makers should forget, is to honor what the patient would want to have done. Physicians and attorneys will agree on that as a matter of both ethics and the law.

Kendall-Raynor, Petra
**Changing perceptions.**
Nursing standard (Royal College of Nursing (Great Britain) : 1987) 2011 Sep 28-Oct 4; 26(4): 24-5

**Abstract:** Media representations of end of life care are often bleak, say nurses at a London hospice. They believe more accurate portrayals in documentaries and dramas would reassure the public that assisted suicide is not the only way to secure a good death.
**Abstract:** Left ventricular assist devices as destination therapy (DT) improve quality of life for many patients with advanced heart failure. However, DT can be associated with risks such as infection, bleeding, and stroke, and may impose psychosocial strain on patients and caregivers. Furthermore, patients treated with DT eventually will die with their device in place whether death is related to the device or not. In response to these concerns, palliative medicine consultation has been suggested with standard DT care to improve focus on quality of life, symptom management, and end-of-life planning. This article reviews key issues associated with caring for patients with DT, including psychosocial, quality-of-life, caregiving, and ethical issues, and discusses end-of-life management of patients with DT, including practical considerations, but moreover, review topics regarding communication, symptom management, and provision of appropriate comfort care.

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different neonatal intensive care units (NICUs).

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**Document 18**

Yun, Young Ho; Han, Kyung Hee; Park, Sohee; Park, Byeong Woo; Cho, Chi-Heum; Kim, Sung; Lee, Dae Ho; Lee, Soon Nam; Lee, Eun Sook; Kang, Jung Hun; Kim, Si-Young; Lee, Jung Lim; Heo, Dae Seog; Lee, Chang Geol; Lim, Yeun Keun; Kim, Sam Yong; Choi, Jong Soo; Jeong, Hyun Sik; Chun, Mison

**Attitudes of cancer patients, family caregivers, oncologists and members of the general public toward critical interventions at the end of life of terminally ill patients.**

*Canadian Medical Association Journal* = *Journal de l'Association medicale canadienne* 2011 Jul 12; 183(10): E673-9

**Abstract:** Whereas most studies have focused on euthanasia and physician-assisted suicide, few have dealt comprehensively with other critical interventions administered at the end of life. We surveyed cancer patients, family caregivers, oncologists and members of the general public to determine their attitudes toward such interventions.

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**Document 19**

Begley, Ann Marie; Glackin, Marie; Henry, Richard

**Tolstoy, stories, and facilitating insight in end of life care: exploring ethics through vicarious experience.**

*Nurse education today* 2011 Jul; 31(5): 516-20

**Abstract:** Facilitating moral insight in end of life care can be challenging, and the purpose of this paper is to illustrate how this can be nurtured by means of creative literature. Tolstoy's Death of Ivan Ilych is presented as an example of such literature. Aristotle's Nichomean Ethics provides the philosophical underpinning for the method used. Sources also include the nursing literature, and students' evaluations of the impact of Tolstoy's novella on their ability to perceive the ethical issues arising in end of life care. Comments from evaluations were analysed and significant themes emerged. Students' comments clearly support the suggestion that use of this novella has facilitated insight into ethical issues at the end of life. Evaluations also indicate that vicarious experience gained through reading this novella has helped to nurture sensitivity and professional insight into the importance of compassion and offering 'comfort' to the dying person.

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**Document 20**

Wald, Hedy S

**Words for the wordless.**

*Journal of general internal medicine* 2011 Jul; 26(7): 817-8

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**Document 21**

Jennings, Bruce

**Unreconcilable differences?**


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Document 22
McCurdy, David
Unreconcilable differences?
The Hastings Center report 2011 Jul-Aug; 41(4): 5-6; author reply 8-9
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Document 23
Jackson, Ann
Unreconcilable differences?
The Hastings Center report 2011 Jul-Aug; 41(4): 6-7; author reply 8-9
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Document 24
Buccafurni, Diana
Unreconcilable differences?
The Hastings Center report 2011 Jul-Aug; 41(4): 7-8; author reply 8-9
Georgetown users check Georgetown Journal Finder for access to full text

Document 25
Miller, Richard B
Unreconcilable differences?
The Hastings Center report 2011 Jul-Aug; 41(4): 8; author reply 8-9
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Document 26
Schildmann, Jan; Hoetzl, Julia; Baumann, Anne; Mueller-Busch, Christof; Vollmann, Jochen
Limitation of treatment at the end of life: an empirical-ethical analysis regarding the practices of physician members of the German Society for Palliative Medicine.
Abstract: To determine the frequencies and types of limitation of medical treatment performed by physician members of the German Society for Palliative Medicine and to analyse the findings with respect to clinical and ethical aspects of end-of-life practices.
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Document 27
Montross, Lori; Winters, Kathryn D; Irwin, Scott A
Dignity therapy implementation in a community-based hospice setting.
Abstract: Dignity Therapy is a brief, empirically supported, individualized psychotherapy designed to address legacy needs among patients at the end of life. To date, this psychotherapy has not been implemented in a "real-world" community-based hospice setting. This study was designed to offer information about the pragmatic aspects of
implementing Dignity Therapy for patients receiving hospice care.

Nyatanga, Brian
Reaching out: doing 'good' in the name of palliative care.

Ko, Danielle N; Perez-Cruz, Pedro; Blinderman, Craig D
Ethical issues in palliative care.
Primary care 2011 Jun; 38(2): 183-93, vii
Abstract: Ethical problems in medicine are common, especially when caring for patients at the end of life. However, many of these issues are not adequately identified in the outpatient setting. Primary care providers are in a unique and privileged position to identify ethical issues, prevent future conflicts, and help patients make medical decisions that are consistent with their individual values and preferences. This article describes some of the more common ethical issues faced by primary care physicians caring for patients with life-limiting illness.

Werb, Ronald
Palliative care in the treatment of end-stage renal failure.
Primary care 2011 Jun; 38(2): 299-309, ix
Abstract: Palliative care begins with establishing goals of care based on estimated prognosis in end-stage renal disease (ESRD). Patients with ESRD are increasingly characterized by older age and multiple comorbid illnesses, and have a mortality rate 8 times higher than the general Medicare population. Dialysis patients are appropriate for palliative care because of their high mortality rate and high symptom burden. More patients and families are choosing not to start or withdraw dialysis for multiple reasons, particularly in patients older than 60 years. Advance directives and resuscitation directives are important in ensuring compassionate and goal-directed palliative care of ESRD patients. Drug toxicities are avoidable by using appropriate drugs at the correct doses and dosing intervals.

Moody, Karen; Siegel, Linda; Scharbach, Kathryn; Cunningham, Leslie; Cantor, Rabbi Mollie
Pediatric palliative care.
Primary care 2011 Jun; 38(2): 327-61, ix
Abstract: Progress in pediatric palliative care has gained momentum, but there remain significant barriers to the appropriate provision of palliative care to ill and dying children, including the lack of properly trained health care professionals, resources to finance such care, and scientific research, as well as a continued cultural denial of death in children. This article reviews the epidemiology of pediatric palliative care, special communication concerns, decision making, ethical and legal considerations, symptom assessment and management, psychosocial issues, provision of care across settings, end-of-life care, and bereavement. Educational and supportive resources for health care practitioners and families, respectively, are included.
Document 32
Pope, Thaddeus M; Arnold, Robert M; Barnato, Amber E
**Introduction. Caring for the seriously ill: cost and public policy.**

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Document 33
Crippen, Dan; Barnato, Amber E
**The ethical implications of health spending: death and other expensive conditions.**

**Abstract:** The cost of health care in the United States has important generational considerations whether analyzed at a point in time, or over many years. The budgets of governments contain important information about the funding of public services, including health care, and the intra- and inter-generational implications of both the inherent tradeoffs, and the particular means of funding the services. End-of-life expenditures, while a significant component of the cost of health care, are not the primary consideration in the ethical or moral questions raised.

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Document 34
Blank, Robert H
**End-of-life decision making across cultures.**
The Journal of law, medicine & ethics : a journal of the American Society of Law, Medicine & Ethics 2011 Summer; 39(2): 201-14

**Abstract:** Even more so than in other areas of medicine, issues at the end of life elucidate the importance of religion and culture, as well as the role of the family and other social structures, in how these issues are framed. This article presents an overview of the variation in end-of-life treatment issues across 12 highly disparate countries. It finds that many assumptions held in the western bioethics literature are not easily transferred to other cultural settings.

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Document 35
Perry, Joshua E; Stone, Robert C
**In the business of dying: questioning the commercialization of hospice.**
The Journal of law, medicine & ethics : a journal of the American Society of Law, Medicine & Ethics 2011 Summer; 39(2): 224-34

**Abstract:** This article critically questions the commercialization of hospice care and the ethical concerns associated with the industry's movement toward "market-driven medicine" at the end of life. For example, the article examines issues raised by an influx of for-profit hospice providers whose business model appears at its core to have an ethical conflict of interest between shareholders doing well and terminal patients dying well. Yet, empirical data analyzing the experience of patients across the hospice industry are limited, and general claims that end-of-life patient care is inferior among for-profit providers or even that their business practices are somehow unseemly when compared to nonprofit providers cannot be substantiated. In fact, non-profit providers are not immune to potentially conflicting concerns regarding financial viability (i.e., "no margin, no mission"). Given the limitations of existing empirical data and contrasting ideological commitments of for-profit versus non-profit providers, the questions raised by this article highlight important areas for reflection and further study. Policymakers and regulators are cautioned to keep ethical concerns in the fore as an increasingly commercialized hospice industry continues to emerge as a dominant component of the U.S. health care system. Both practitioners and researchers are encouraged to expand their efforts to better understand how business practices and commercial interests may compromise the death process of the
patient and patient's family—a process premised upon a philosophy and ethical tradition that earlier generations of hospice providers and proponents established as a trusted, end-of-life alternative.

Document 36
Aktas, Aynur; Walsh, Declan
Methodological challenges in supportive and palliative care cancer research.
Seminars in oncology 2011 Jun; 38(3): 460-6
Abstract: As a growing medical field, palliative and supportive care should incorporate evidence-based medical practice. The gold standard research method continues to be the randomized clinical trial. This has been pursued with regard to cancer trials focused on cure. It has specific operational and methodological challenges in advanced disease. There are numerous reasons why effective research in palliative and supportive care is difficult. A consensus on the best research strategies and design is lacking. We will discuss the principles of palliative and supportive care research, examine the inherent challenges particularly in randomized controlled trials, and offer some suggestions to overcome them.

Document 37
Bharadwaj, Parag; Ward, Katherine T
Palliative sedation for a patient with terminal illness.
American family physician 2011 May 1; 83(9): 1094-6

Document 38
Vlug, Mariska G; de Vet, Henrica C W; Pasman, H Roeline W; Rurup, Mette L; Onwuteaka-Philipsen, Bregje D
The development of an instrument to measure factors that influence self-perceived dignity.
Journal of palliative medicine 2011 May; 14(5): 578-86
Abstract: Preserving dignity can be considered as a goal of palliative care. To provide dignity-conserving care, it is relevant to identify the factors that influence a patient's self-perceived dignity. This study aims to develop an instrument to measure factors affecting self-perceived dignity that has good content validity and is appropriate for use in practice.

Document 39
Blinderman, Craig D; Prager, Kenneth
The right to information—a first step toward improving end-of-life care.

Document 40
Cherrington, Venus
Ensuring a dignified and culturally safe death.
Nursing New Zealand (Wellington, N.Z. : 1995) 2011 May; 17(4): 14-6
Ruler, Amanda
**Examining end-of-life care issues.**

Brown, Hilary; Johnston, Bridget; Ostlund, Ulrika
**Identifying care actions to conserve dignity in end-of-life care.**
British journal of community nursing 2011 May; 16(5): 238-45

**Abstract:** Community nurses have a central role in the provision of palliative and end-of-life care; helping people to die with dignity is an important component of this care. To conserve dignity, care should comprise a broad range of actions addressing the distress that might impact on the patient's sense of dignity. These care actions need to be defined. This study aims to suggest care actions that conserve dignity at the end of life based on evidence from local experience and community nursing practice. Data were collected by focus group interviews and analysed by framework analysis using the Chochinov model of dignity as a predefined framework. Suggestions on care actions were given in relation to all themes. As part of a multi-phase project developing and testing a dignity care pathway, this study might help community nurses to conserve dying patients' dignity.

Hall, Kelley
**Professional boundaries: building a trusting relationship with patients.**
Home healthcare nurse 2011 Apr; 29(4): 210-7

**Abstract:** As an education coordinator working for a rural hospice agency, I orient new staff, including nurses, aides, social workers, chaplains, and even volunteers on professional boundaries. Over the years, some of the stories about boundaries have been entertaining. Sometimes the crossing of boundaries has been minor, although, at times, looking back, the stories concerning boundary violations have made me question the judgment of some of my peers.

Wolff, A; Browne, J; Whitehouse, W P
**Personal resuscitation plans and end of life planning for children with disability and life-limiting/life-threatening conditions.**
Archives of disease in childhood. Education and practice edition 2011 Apr; 96(2): 42-8

**Abstract:** This article discusses the need for person-specific planning for the increasing numbers of disabled children with life-limiting and life-threatening conditions. It describes the system developed in Nottingham for this client group to have a family-held personal resuscitation plan, (PRP) which is developed with the child and family by their lead paediatrician. The PRP is an emergency medical care plan which supports the provision of the most appropriate level of intervention for the child whether they are at home, school, short break unit or hospital. The PRP template is presented with advice on implementation and case examples. Feedback from families, medical and nursing staff is that PRPs are useful and empowering. The system supports timely discussions about appropriate care in an emergency and the communication of decision made jointly by the child, family and medical team to all concerned. A flexible and person-specific PRP stating what interventions to do such as airway clearance, facial oxygen, trial of bag and mask ventilation is preferable to a do not attempt resuscitation form which is an 'all or nothing system' and
can seem very negative to families. A PRP in the home can support appropriate action from local rapid response teams set up to review unexpected child deaths.

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**Document 45**

Mailly, Maryse; Bourrié, Danièle; Escassut, Pascal; Cadilhac, Marie-Bernadette; Guldner, Elisabeth

*The principle of double effect in palliative care. = Le principe du double effet en soins palliatifs.*

Soins; la revue de référence infirmière 2011 Apr(754): 45-6

**Abstract:** Caregivers sometimes feel powerless in complex end-of-life situations. Some therapies used to relieve the patient can have the effect of shortening the patient's life. This is why it is essential to explain clearly the principle known as the double effect.

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**Document 46**

Hügler, Stephanie

*Hospices - a place to die with dignity. = Hospize - ein Ort um menschenwürdig zu sterben.*

Deutsche medizinische Wochenschrift (1946) 2011 Apr; 136(16): p12

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**Document 47**

Janvier, Annie; Okah, Felix; Farlow, Barbara; Lantos, John D

*An infant with trisomy 18 and a ventricular septal defect.*

Pediatrics 2011 Apr; 127(4): 754-9

**Abstract:** Decisions for critically ill infants with trisomy 18 raise thorny issues about values, futility, the burdens of treatment, cost-effectiveness, and justice. We presented the case of an infant with trisomy 18 to 2 neonatologists with experience in clinical ethics, Annie Janvier and Felix Okah, and to a parent, Barbara Farlow. They do not agree about the right thing to do.

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**Document 48**

Hanna, Nader N; Bellavance, Emily; Keay, Timothy

*Palliative surgical oncology.*

The Surgical clinics of North America 2011 Apr; 91(2): 343-53, viii

**Abstract:** Palliative surgical oncology is a relatively new concept, but builds on a long tradition in surgery. As the field of palliative medicine grows and becomes its own specialty, surgeons have been receiving some specialized training in palliative care; devising specific palliative surgical procedures; and reevaluating the ethics of their interactions with patients, especially for the selection of palliative surgical procedures. This is leading to a new form of surgical practice in which the emphasis is on relief of present or anticipated symptoms, even if the interventions do not prolong a patient's life span.

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**Document 49**

Daher, Michel
Opioids for cancer pain in the Middle Eastern countries: a physician point of view
Journal of Pediatric Hematology/Oncology 2011 April; 33(Suppl. 1): S23-S28
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Document 50
Hablas, Ahmed
Palliative care in Egypt: challenges and opportunities
Journal of Pediatric Hematology/Oncology 2011 April; 33 (Suppl. 1): S52-S53
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Document 51
Shad, Aziza; Ashraf, Muhammad Shamvil; Hafeez, Haroon
Development of palliative-care services in a developing country: Pakistan
Journal of Pediatric Hematology / Oncology 2011 April; 33( Suppl. 1): S62-S63
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Document 52
Elcigil, Ayfer
The current status of palliative care in Turkey: a nurse's perspective
Journal of Pediatric Hematology / Oncology 2011 April; 33 (Suppl. 1): S70-S72
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Document 53
Komurcu, Seref
Current status of palliative care in Turkey
Journal of Pediatric Hematology/ Oncology 2011 April; 33(Suppl. 1): S78-S80
Georgetown users check Georgetown Journal Finder for access to full text

Document 54
Shawawra, Mousa; Khleif, Amal Dweib
Palliative care situation in Palestinian Authority
Journal of Pediatric Hematology / Oncology2011 April; 33(Suppl. 1): S64-S67
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Document 55
Sanz Ortiz, Jaime
[Chemotherapy at the end of life. Is it compassionate?]. = Quimioterapia en la fase final de la vida: ¿es compasiva?
Medicina clinica 2011 Mar 26; 136(8): 343-4
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**Document 56**

Lynøe, Niels; Juth, Niklas

*[How to define death help?]* = *Hur ska man definiera dödshjälp?*

*Tidsskrift for den Norske lægeforening : tidsskrift for praktisk medicin, ny række* 2011 Mar 4; 131(5): 443

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**Document 57**

Primavera-Lévy, Elisa

*Facing pain: Dr. Hans Killian's photo book, Facies dolorosa.*

*Literature and medicine* 2011 Spring; 29(1): 1-38

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**Document 58**

Pignotti, Maria Serenella

*If Arielle were Italian.*


Georgetown users check [Georgetown Journal Finder](https://journal.findit.nu) for access to full text

**Document 59**

Devictor, Denis; Marraro, Giuseppe

*Global versus local bioethics.*


Georgetown users check [Georgetown Journal Finder](https://journal.findit.nu) for access to full text

**Document 60**

Smith, Beverley

*The worst infraction of all.*

*Palliative & supportive care* 2011 Mar; 9(1): 111

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**Document 61**

Tan, Y S; Cheong, P Y

*Experiences in caring for the dying: a doctor’s narratives.*

*Singapore medical journal* 2011 Mar; 52(3): 140-5

**Abstract:** The study of narratives is increasingly noted for its value in the professional and personal development of doctors. We present the narratives of one of the author's experiences in the care of dying patients over a span of three decades. From the narratives, we identified three paradigms with which doctors respond to and care for dying
patients and their families: 'No death', where there is a general denial of death and dying; 'Death', where the care provider's focus is directed to the facilitation of a 'good' death; and 'Life', where the doctor responds to the patients' death and dying as integrated and inseparable aspects of the patient's and family's life. The origins and implications of the paradigms are discussed. In addition to good communication, these narratives underscore the importance of personal reflection and insight when providing end-of-life care.

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**Document 62**

Geppert, Cynthia M A; Rabjohn, Patrick; Vlaskovits, Joseph

*To treat or not to treat: psychosis, palliative care, and ethics at the end-of-life: a case analysis.*

Psychosomatics 2011 Mar-Apr; 52(2): 178-84

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**Document 63**

Baumrucker, Steven; Mingle, Paige; Harrington, Dianne; Stolick, Matt; Carter, Gregory T; Oertli, Karrie A

*Medical marijuana and organ transplantation: drug of abuse, or medical necessity?*

The American journal of hospice & palliative care 2011 Mar; 28(2): 130-4

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**Document 64**

Enck, Robert E

*Intensive care unit palliative medicine: some issues--part I.*

The American journal of hospice & palliative care 2011 Mar; 28(2): 73-4

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**Document 65**

Doorenbos, Ardith Z; Abaquin, Carmencita; Perrin, Margot E; Eaton, Linda; Balabagno, Araceli O; Rue, Tessa; Ramos, Rita

*Supporting dignified dying in the Philippines.*


*Abstract:* This study aimed to assess the appropriateness of the International Classification for Nursing Practice (ICNP) Palliative Care for Dignified Dying catalogue for palliative nursing in the Philippines.

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**Document 66**

Fromme, Erik K; Guthrie, Amy E; Grueber, Cynthia M

*Transitions in end-of-life care: the Oregon trail.*

Frontiers of health services management 2011 Spring; 27(3): 3-16

*Abstract:* Hospitals can create an environment that supports patients, families, and healthcare professionals so that they are better able to recognize the best way to care for each patient during times of transition. This article highlights some of the supports intentionally put into place to assist patients, family, and staff through difficult transitions at Oregon Health & Science University. These supports include an expert inpatient and outpatient palliative care team to coach patients, families, and staff at the bedside; statewide efforts to raise the skill level of
all healthcare professionals through education; and the Physician Orders for Life-Sustaining Treatment (POLST) program, which helps ensure that care decisions made in one setting are respected as the patient moves to another care setting.

Document 67
Weeks, William Brinson; Nelson, William A
**Ethical issues arising from variation in health services utilization at the end of life.**
Frontiers of health services management 2011 Spring; 27(3): 17-26

**Abstract:** Research on health services delivery, particularly at the end of life, has demonstrated that more care does not necessarily lead to better technical quality, patient satisfaction, or outcomes. These findings raise three ethical issues: (1) justice in the allocation of scarce resources across health service areas; (2) nonmaleficence in the provision of appropriate amounts of care to patients; and (3) transparency about local healthcare practice so patients can make enlightened decisions about healthcare choices. We conclude that in this era of healthcare accountability, managers and clinicians can use these ethical principles to drive change in the process of providing more efficient, more effective, and more patient-centered care, especially at the end of life.

Document 68
Barrett, Pamela M
**A good death: changing the script for end-of-life care.**
Frontiers of health services management 2011 Spring; 27(3): 27-33

Document 69
Ahern, Patricia
**Death as a life event: better palliative and end-of-life care.**
Frontiers of health services management 2011 Spring; 27(3): 35-41

Document 70
Krakauer, Randall
**Invictus: increasing patient choice in advanced illness and end-of-life care.**
Frontiers of health services management 2011 Spring; 27(3): 43-8

Document 71
**Policy statement: decisions near the end of life.**
Frontiers of health services management 2011 Spring; 27(3): 49-51
**Document 72**

Ismail, A; Long, J; Moiemen, N; Wilson, Y

**End of life decisions and care of the adult burn patient.**


**Abstract:** Despite advancements in the provision of burn care, there is still a significant cohort of patients who fail to respond to therapy or for whom treatment is deemed futile. The decision to withdraw support from, or to implement a Do-Not-Resuscitate (DNAR) order in, such patients can be challenging. Our aims were to review the withdrawal of life-sustaining treatment, issuing of DNAR orders and end of life care in burn patient deaths.

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**Document 73**

Lamba, Sangeeta; Quest, Tammie E

**Hospice care and the emergency department: rules, regulations, and referrals.**

Annals of emergency medicine 2011 Mar; 57(3): 282-90

**Abstract:** Emergency clinicians often care for patients with terminal illness who are receiving hospice care and many more patients who may be in need of such care. Hospice care has been shown to successfully address the multidimensional aspects of the end-of-life concerns of terminally ill patients: dying with dignity, dying without pain, reducing the burden on family and caregivers, and achieving a home death, when desired. Traditional emergency medicine training may fail to address hospice as a system of care. When they are unfamiliar with the hospice model, emergency clinicians, patients, and caregivers may find it difficult to properly use and interact with these care services. Potential poor outcomes include the propagation of misleading or inaccurate information about the hospice system and the failure to guide appropriate patient referrals. This article reviews the hospice care service model and benefits offered, who may qualify for hospice care, common emergency presentations in patients under hospice care, and a stepwise approach to initiating a hospice care referral in the emergency department.

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**Document 74**

Abrahm, Janet L

**Advances in palliative medicine and end-of-life care.**


**Abstract:** Palliative care improves the quality and cost-effectiveness of adult and pediatric patient care, and it decreases unwanted hospitalizations and aggressive care at the end of life. National palliative care quality standards and preferred practices can be used for benchmarking by institutions, health care systems, and accrediting bodies. Pain and symptom management and the management of delirium for patients is now possible for the vast majority of patients, even those with advanced disease. However, because of shortages of specialists providing "tertiary" palliative care, significant improvements are needed in generalist-level palliative care among oncologists, intensivists, and specialists caring for patients with advanced cardiac, pulmonary, renal, and hepatic diseases. POLST (Physician Orders for Life-Sustaining Treatment) forms are a major advance in end-of-life care. They enable patients' advance directives to be valid wherever they are cared for (home, hospital, or nursing facility).

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**Document 75**

Đorđević Veljko; Braš Marijana; Milunović Vibor; Brajković Lovorka; Stevanović Ranko; Polašek Ozren

**The founding of the Centre for Palliative Medicine, Medical Ethics and Communication Skills: a new step toward the development of patient-oriented medicine in Croatia.**

Croatian medical journal 2011 Feb 15; 52(1): 87-8

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Document 76
Baumann, Antoine; Claudot, Frédérique; Audibert, Gérard; Mertes, Paul-Michel; Puybasset, Louis
The ethical and legal aspects of palliative sedation in severely brain-injured patients: a French perspective.
Philosophy, ethics, and humanities in medicine : PEHM 2011 February 8; 6: 4
Abstract: To fulfill their crucial duty of relieving suffering in their patients, physicians may have to administer palliative sedation when they implement treatment-limitation decisions such as the withdrawal of life-supporting interventions in patients with poor prognosis chronic severe brain injury. The issue of palliative sedation deserves particular attention in adults with serious brain injuries and in neonates with severe and irreversible brain lesions, who are unable to express pain or to state their wishes. In France, treatment limitation decisions for these patients are left to the physicians. Treatment-limitation decisions are made collegially, based on the presence of irreversible brain lesions responsible for chronic severe disorders of consciousness. Before these decisions are implemented, they are communicated to the relatives. Because the presence and severity of pain cannot be assessed in these patients, palliative analgesia and/or sedation should be administered. However, palliative sedation is a complex strategy that requires safeguards to prevent a drift toward hastening death or performing covert euthanasia. In addition to the law on patients' rights at the end of life passed in France on April 22, 2005, a recent revision of Article 37 of the French code of medical ethics both acknowledges that treatment-limitation decisions and palliative sedation may be required in patients with severe brain injuries and provides legal and ethical safeguards against a shift towards euthanasia. This legislation may hold value as a model for other countries where euthanasia is illegal and for countries such as Belgium and Netherlands where euthanasia is legal but not allowed in patients incapable of asking for euthanasia but in whom a treatment limitation decision has been made.
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Document 77
Hatano, Yutaka; Yamada, Miwa; Fukui, Kenji
Shades of truth: cultural and psychological factors affecting communication in pediatric palliative care.
Abstract: Communication with children who have life-threatening illnesses is a major challenge. Communication practices are greatly influenced by factors such as the child's age, the parents' wishes, and the cultural norms. This article presents the case of a 12-year-old Japanese boy with advanced hepatoblastoma. The patient also was diagnosed with Asperger's syndrome, which impairs interpersonal communication. The case is discussed from the perspective of clinical ethics, especially with regard to truth telling. The health care team faced an ethical dilemma because of the complications involved. Physicians treating children with cancer should be aware of these issues to be able to effectively communicate with their patients.
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Document 78
Lu, Chu-Yun; Johantgen, Meg
Factors associated with treatment restriction orders and hospice in older nursing home residents.
Journal of clinical nursing 2011 Feb; 20(3-4): 377-87
Abstract: The purpose of the study is to examine factors associated with do-not-resuscitate orders, do-not-hospitalise orders and hospice care in older nursing home residents at admission.
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Document 79
Hilliar, Marie T.
Utilitarianism impacting care of those with disabilities and those at life's end
The Linacre Quarterly 2011 February; 78(1): 59-71
Document 80
Mallery, Laurie H; Moorhouse, Paige
Respecting frailty.
Journal of medical ethics 2011 Feb; 37(2): 126-8
Abstract: While the medical treatment of older individuals often results in desirable outcomes, indiscriminate use of aggressive treatment at the end-of-life can cause paradoxical harm and suffering. Comprehensive assessment and communication can help foster decisions that consider the effect of frailty on health outcomes.

Document 81
Daher, Michel
Gaps in end-of-life care.
Abstract: End-of-life care is an important aspect of medical practice. Individual physicians and the medical community must be committed to the compassionate and competent provision of care to dying patients and their families. Patients rightfully expect their physicians to care for them and provide them with medical assistance as they are dying. To care properly for patients near the end of life, the physician must understand that palliative care entails addressing physical, psychosocial, and spiritual needs and that patients may at times require palliative treatment in an acute care context. To provide palliative care, the physician must be up to date on the proper use of opioids and the legality and propriety of using high doses of opioids as necessary to relieve suffering. Good symptom control; ongoing involvement with the patient; and physical, psychological, and spiritual support are the hallmarks of quality end-of-life care. Care of patients near the end of life, however, has a moral, psychological, and interpersonal intensity that distinguishes it from most other clinical encounters. With appropriate education, physicians can play a key role to improve care for patients and families who are living with advanced life-threatening illness. Although some issues (e.g., the role of physician-assisted death in addressing suffering) remain very controversial, there is much common ground based on the application of the four major principles of medical ethics, nonmaleficence, beneficence, autonomy, and justice.

Document 82
Toh, Han Chong
Providing hope in terminal cancer: when is it appropriate and when is it not?
Annals of the Academy of Medicine, Singapore 2011 Jan; 40(1): 50-6
Abstract: Hope is essential in the face of terminal cancer. Generally in Western societies, patients and their families prefer their doctor to engage them in transparent, realistic, authoritative, empathic and open communication about the diagnosis and prognosis of cancer but this topic is not well studied in the Asian context. With the exponential increase in information about cancer and the many permutations in cancer treatment, rational and otherwise, the doctor-patient relationship is even more critical in planning the best treatment strategy and also in rendering both particular and general hope in the patient's war against cancer. Overall, the majority of drugs tested against cancer have failed to reach the market, and those that have, only provide modest benefits, several major therapeutic breakthroughs notwithstanding. Commodified medicalisation of the dying process ingrained into the contemporary consciousness can potentially create unrealistic or false hope, therapeutic nihilism and a drain on the resources of both the patient and society. These factors can also detract from the dignity of dying as an acceptable natural process. Hope cannot be confined only to focusing merely on the existential dimension of improving survival through technological intervention. Psychosocial and, where appropriate, spiritual interventions and support also play major roles in relieving suffering and providing hope to the patient. Hope cannot be a victim of misinformation from self-interested external parties, nor be an obsession with just buying promises of extending survival time without sufficient regard for quality of life and achieving a good death.
'Early terminal sedation' is a distinct entity.

Abstract: There has been much discussion regarding the acceptable use of sedation for palliation. A particularly contentious practice concerns deep, continuous sedation given to patients who are not imminently dying and given without provision of hydration or nutrition, with the end result that death is hastened. This has been called 'early terminal sedation'. Early terminal sedation is a practice composed of two legally and ethically accepted treatment options. Under certain conditions, patients have the right to reject hydration and nutrition, even if these are life-sustaining. Patients are also entitled to sedation as palliation for intolerable, intractable suffering. Though early terminal sedation is thought to be rare at present, the changing nature of palliative medicine suggests its use will increase. Arguments regarding early terminal sedation have failed to recognize early terminal sedation as a distinct legal and ethical entity. It can be seen as both the simple sum of treatment refusal and sedation for palliation, analogous to terminal sedation. It can also be seen as an indivisible palliative treatment, more analogous to assisted suicide or euthanasia. But ultimately, it is wholly analogous neither to terminal sedation given when death is imminent, nor to assisted suicide or euthanasia. This paper contends that early terminal sedation should be considered as a distinct entity. Such a reconception promises to provide a way forward in the debate, practice and policy regarding this contentious area of palliative medicine.
Document 88
Martin, Gary A. and Sabbagh, Marwan N.
PALLIATIVE CARE FOR ADVANCED ALZHEIMER'S AND DEMENTIA: GUIDELINES AND STANDARDS FOR EVIDENCE-BASED CARE
Call number: RC522 .P35 2011

Document 89
Kinzbrunner, Barry M. and Policzer, Joel S., eds.
END-OF-LIFE CARE: A PRACTICAL GUIDE
Call number: R726.8 .A15 2011

Document 90
Bishop, Jeffrey P.
THE ANTICIPATORY CORPSE: MEDICINE, POWER, AND THE CARE OF THE DYING

Document 91
Maio, Giovanni
Can help for patients be too expensive? Ethical considerations and end-stage lung disease.
Respiration; international review of thoracic diseases 2011; 82(5): 395-9
Abstract: The treatment of patients with end-stage lung disease is very expensive. In an era of cost containment, the physician could be forced to restrict his therapy in order to spend less. But does the physician really have the right to restrict a reasonable therapy for economic reasons? It is argued that the mission of medicine is to help people in need and that any confidence is shaken if the physician is forced to be both physician and gatekeeper at the same time. It is argued that medicine as a central form of care will only be able to survive if it has the chance to remain a free profession, a profession which has the liberty to help each individual patient even if this help is expensive. However, it remains a duty of the physician to accept limits and to learn that for a good death it is necessary to be honest and to talk early enough about the possibilities of palliative care.

Document 92
Newbury, Jenny
Reflexivity in a study of family carers in home palliative care: a personal account.
Nurse researcher 2011; 19(1): 30-6
Abstract: To discuss a personal account of the role of reflexivity in a qualitative, grounded theory study with family carers in home palliative care.

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Document 93

de Vries, A J Hans; van Wijlick, Eric H J; Blom, Jaap M; Meijer, Ina; Zijlstra, Jan G

[When the end is near: an ICU patient who died at home]. = Als het einde gekomen is: een IC-patiënt die thuis sterft.

Nederlands tijdschrift voor geneeskunde 2011; 155(26): A3025

Abstract: We describe the process of transferring a 64-year-old male from a Dutch intensive care unit to his home so that he could die there. He was a respirator-dependent cardiac surgical patient; his intensive care treatment had been withdrawn. We describe the requirements regarding the transfer of care, the role of the nursing staff and documentation of the process. We discuss the natural cause of death and subsequent administrative steps. Based on the positive reactions of the patient and his family, we propose to incorporate this process into Dutch intensive care practice guidelines.

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Document 94

Engström, Ingemar; Eckerdal, Gunnar

[Time limit for palliative sedation is needed]. = Tidsgräns för palliativ sедерing behövs.

Läkartidningen 2010 Dec 22; 107(51-52): 3297

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Document 95

Skröder, Richard; Fürst, Carl Johan; Todoulos, Eva Thorén

[A reply about palliative care: it's all about the patient]. = Replik om palliativ vård: det ar patienten det handlar om.

Läkartidningen 2010 Dec 22; 107(51-52): 3304

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Document 96

Chevrolet, Jean-Claude; Janssens, Jean-Paul; Adler, Dan


Revue médicale suisse 2010 Dec 15; 6(275): 2390-5

Abstract: Non-invasive mechanical ventilation in patients with chronic neuromuscular disorders is an effective tool for treating dyspnea or sleep disturbances often observed in such patients. So, NIV has to be considered as a palliative treatment and it must systematically be offered to these patients. Mechanical ventilation, non-invasive or invasive (via a trachesotomy) have to be considered systematically with patients and families at an earlier stages of these diseases in order to design a strategy in case of acute respiratory failure. In a second parent paper of this issue, we discuss the medico-legal implications of mechanical ventilation in neuromuscular failure, particularly the end-of-life aspects.

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Document 97

Christie, Bryan

Legal move to help terminally ill people to die rejected in Scotland.

BMJ (Clinical research ed.) 2010 December 3; 341: c6986
Document 98
Zamperetti, Nereo; Piccinni, Pasquale
**Intensivists managing end-of-life care: dwarfs without giants' shoulders to stand upon.**
Intensive care medicine 2010 Dec; 36(12): 1985-7

Document 99
Saunders, John
**Oral feeding: practical care at the end of life.**

Document 100
Penderell, Adrienne; Brazil, Kevin
**The spirit of palliative practice: a qualitative inquiry into the spiritual journey of palliative care physicians.**
Palliative & supportive care 2010 Dec; 8(4): 415-20
**Abstract:** Much is known about the important role of spirituality in the delivery of multidimensional care for patients at the end of life. Establishing a strong physician-patient relationship in a palliative context requires physicians to have the self-awareness essential to establishing shared meaning and relationships with their patients. However, little is known about this phenomenon and therefore, this study seeks a greater understanding of physician spirituality and how caring for the terminally ill influences this inner aspect.

Document 101
Wein, Simon
**Dignity: a fight to the end, or an end to the fight?**
Palliative & supportive care 2010 Dec; 8(4): 391-3

Document 102
Roy, David J
**And pain shall have no dominion?**

Document 103
Hansen, Deborah
**Dying under a cloud.**
Levenson, Steven A

**The health care decision-making process framework.**

Maryland medicine : MM : a publication of MEDCHI, the Maryland State Medical Society 2010 Winter; 11(1): 13-7

**Abstract:** Health care decision making is a process that includes definable steps in a desirable sequence. The process is universally relevant (i.e., it applies in all settings) and enduring (i.e., it has remained applicable over time and will continue to apply in the future). Physicians play an essential role in the health care decision-making process. Learning to follow desired approaches at each step (e.g., optimal approaches to defining DMC) facilitates and improves the quality and pertinence of physician participation. Generally, diligent adherence to the steps in this process is likely to yield the best possible results—they are consistent with patient needs and values while facilitating pertinent utilization of health care resources—under often challenging and imperfect circumstances. Thus, the health care decision-making process constitutes a key component of the improvement and reform of health care, which is currently under much critical scrutiny.

Families' perceptions of inpatient and home hospice care at end-of-life.

Archives of internal medicine 2010 Nov 8; 170(20): 1856-7

De Sousa, Maysa; Smith, Dawn; Corcoran, Amy; Bailey, F Amos; Furman, Christian; Ritchie, Christine; Rosenfeld, Kenneth; Shreve, Scott; Casarett, David

**Families’ perceptions of inpatient and home hospice care at end-of-life.**

Archives of internal medicine 2010 No 8; 170(20): 1856-7

Pediatric palliative care in childhood cancer nursing: from diagnosis to cure or end of life.

Seminars in oncology nursing 2010 Nov; 26(4): 205-21

**Abstract:** To describe selected components of pediatric palliative care from diagnosis to cure or end of life that combine to help nurses and other clinicians achieve goals of care for children with cancer and their families.

Monedero, P; Navia, J

[Limiting therapeutic intervention and euthanasia: making decisions and resolving conflicts in end-of-life-care]. = Limitación del esfuerzo terapéutico y eutanasia: toma de decisiones y resolución de conflictos en el
paciente crítico.
Revista española de anestesiología y reanimación 2010 Nov; 57(9): 586-93
Georgetown users check Georgetown Journal Finder for access to full text

Document 109
Baumrucker, Steven J; Stolick, Matt; Carter, Gregory T; Lasky, Tiffany M; Sheldon, Joanne E; Harrington, Dianne; Messerschmidt, William H; Oertli, Karrie A; Morris, Gerald M
Death, dying, and statistics: quality measures versus quality of life.
The American journal of hospice & palliative care 2010 Nov; 27(7): 494-9
Georgetown users check Georgetown Journal Finder for access to full text

Document 110
Shovelton, Dame Helena
Give COPD patients the right to end of life care.
Nursing times 2010 Nov 9-15; 106(44): 27
Georgetown users check Georgetown Journal Finder for access to full text

Document 111
Dugdale, Lydia
The art of dying well.
The Hastings Center report 2010 Nov-Dec; 40(6): 22-4
Georgetown users check Georgetown Journal Finder for access to full text

Document 112
Leijonhufvud, Madeleine; Lynøe, Niels
[Sedation therapy which shortens life–homicide or adequate treatment?]. = Sederingsterapi som förkortar livet –dråp eller adekvat behandling?
Läkartidningen 2010 Nov 10-16; 107(45): 2772-3
Georgetown users check Georgetown Journal Finder for access to full text

Document 113
Schildmann, J; Vollmann, J
Deutsche medizinische Wochenschrift (1946) 2010 Nov; 135(45): 2230-4
Abstract: BACKGROUND AND RESEARCH QUESTION: Physicians' decisions regarding the indication of medical treatment are central to the application or limitation of medical measures in advanced cancer. This qualitative study explores criteria and procedural aspects of treatment decisions with patients with cancer near the end of life from the perspective of oncologists. RESEARCH PARTICIPANTS AND METHODS: In this qualitative interview study physicians working in the field of oncology were asked about their decisional criteria and procedural aspects of treatment decision making in cases of patients with advanced cancer. All interviews were audiotaped and transcribed. Qualitative data analysis was conducted in accordance with principles of "Grounded Theory".
RESULTS: 17 research interviews had been analysed. Next to medical criteria the life-circumstances of the patients with respect to age and social situation as well as the perceived quality of the physician-patient-relationship were named as foundation for decisions about the application or limitation of medical treatment at the end of life. In addition situational factors such as time pressure or the available technical equipment were cited as relevant factors for the decisions. "Silent acquiescence" as the predominant decision making model which has been reconstructed on the basis of the narratives means that decisions about the limitation of medical treatment are not communicated explicitly within the physician-patient-relationship. This approach was justified by the interviewees in light of the long standing relationship between physicians and patients. CONCLUSIONS: The decisional criteria and procedural aspects of decision making in patients with advanced cancer which have been elicited in this qualitative study inform the current scientific and societal debate on ethically relevant aspects of end-of-life decision making in medicine.

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**Document 114**

Curtis, J Randall; Vincent, Jean-Louis

**Ethics and end-of-life care for adults in the intensive care unit.**

Lancet 2010 Oct 16; 376(9749): 1347-53

**Abstract:** The intensive care unit (ICU) is where patients are given some of the most technologically advanced life-sustaining treatments, and where difficult decisions are made about the usefulness of such treatments. The substantial regional variability in these ethical decisions is a result of many factors, including religious and cultural beliefs. Because most critically ill patients lack the capacity to make decisions, family and other individuals often act as the surrogate decision makers, and in many regions communication between the clinician and family is central to decision making in the ICU. Elsewhere, involvement of the family is reduced and that of the physicians is increased. End-of-life care is associated with increased burnout and distress among clinicians working in the ICU. Since many deaths in the ICU are preceded by a decision to withhold or withdraw life support, high-quality decision making and end-of-life care are essential in all regions, and can improve patient and family outcomes, and also retention of clinicians working in the ICU. To make such a decision requires adequate training, good communication between the clinician and family, and the collaboration of a well functioning interdisciplinary team.

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**Document 115**

Brkljacic Zagrovic, Morana

[Palliative medicine–linkage of expert human care for the terminally ill and medical ethics]. = Palijativna medicina–spoj strucne humane skrbi za terminalno oboljele i medicinske etike.


**Abstract:** Palliative medicine is a new branch of medicine dealing with optimal quality of life and death, and is primarily a medical area of interest. Palliative care is a care provided by interdisciplinary palliative team. Let us remember that palliative care is a specific form of medical care for patients in the terminal phase of life. It is an approach to improve the quality of life of patients faced with fatal diseases, and of their families. Palliative care starts when classic methods of treatment have been exhausted, or when the symptoms of a malignant disease reach a level that the patient can hardly endure. It encompasses three areas: alleviating the symptoms, giving psycho-sociological support to patients and their caregivers, and dealing with ethical problems concerning the end of life. Particularly important is the ethics of palliative care, because it is focused on the aspects of care aimed at the patient and critical decision-making. The decisions made in palliative medicine require moral, legal and medical judgments. At the same time, one must strike a balance between clinical aspects of care and the patient's autonomy regarding his wishes, beliefs, and finally decisions about his own medical treatment. Ethical aspects of decision-making cannot be separated from clinical circumstances in the individual case, in the same way as medical decision-making cannot neglect the four (bio)ethical principles: beneficence, non-maleficence, autonomy of the person, and justice.

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Learning from dying patients during their final days: life reflections gleaned from dignity therapy.

Abstract: Dignity therapy is a novel therapeutic approach designed to decrease suffering, enhance quality of life and bolster a sense of dignity for patients approaching death. The benefits of dignity therapy were previously documented in a sample of 100 terminally ill patients. One of the products of dignity therapy is a transcript of the edited therapy session(s). In this qualitative study, 50 of the 100 (17 from Winnipeg, Manitoba, Canada, and 33 from Perth, Australia) dignity therapy transcripts were randomly drawn, and independently coded and analysed by three investigators using a grounded theory approach. The transcripts revealed that dignity therapy serves to provide a safe, therapeutic environment for patients to review the most meaningful aspects of their lives in such a manner that their core values become apparent. The most common values expressed by the patients included 'Family', 'Pleasure', 'Caring', 'A Sense of Accomplishment', 'True Friendship', and 'Rich Experience'. Exemplars of each of these values illustrate the pervasive, defining role of values in our lives. The findings are discussed in terms of values theory, the role of dignity therapy, and consideration of values clarification in clinicians’ efforts to enhance the dignity of terminally ill patients.

Morality and moral conflicts in hospice care: results of a qualitative interview study.

Abstract: Hospices consider themselves places that practise a holistic form of terminal care, encompassing physical and psychological symptoms, and also the social and spiritual support for a dying patient. So far, the underlying ethical principles have been treated predominantly in terms of a normative theoretical discussion. The interview study discussed in this paper is a qualitative investigation into general and hospice-related conceptions of morality among full-time and voluntary workers in German inpatient hospices. It examines moral conflicts and efforts leading to their solution. The main ideas identified include moral neutrality towards the patients and their requests, the capability of acceptance, the idea of self-restraint with respect to the dying patient and the principle of respect for the natural course of dying. Essential triggers for moral conflicts were the inadequate education of patients, problems of acceptance in view of incurable disease, and disagreements between members of patients’ families. The interviewees expressed their scepticism towards formal institutions of ethical counselling. The study has shown a type of virtue ethics that forms an integral part of the overall concept of hospice care, which cannot be treated separately from a holistic idea of care at the end of life.

The critical role of religion: caring for the dying patient from an Orthodox Jewish perspective.

Abstract: Culturally competent medical care for the dying patient by families and health care professionals is a challenging task especially when religious values, practices, and beliefs influence treatment decisions for patients at the end of life. This article describes end-of-life guidelines for hospital health care professionals caring for Orthodox Jewish patients and their families. Religious perspectives on advance directives, comfort care and pain control, nutrition and hydration, do not resuscitate/do not intubate (DNR/DNI), and extubation are often unfamiliar to the American medical community.
**Document 119**

Fine, Robert L

**Keeping the patient at the center of patient- and family-centered care.**


**Abstract:** The practice of palliative care typically refers to the focus of treatment as the patient and family. Tending to the needs of both patients and their families is usually good, but what should clinicians do when they perceive the best interests, needs, or treatment preferences of the patient are in conflict with those of the family or other surrogate? Physicians may be able to suppress the inevitable moral cognitive dissonance of such circumstances, write orders, and walk away, but other health care professionals, especially nurses, may not have it so easy. This article suggests practical steps to obviate conflict in such circumstances before offering an ethical analysis focusing on notions of autonomy, beneficence, and true caring for patients, especially those near the end of life. The limitations of surrogate decision makers are considered and legal liability concerns are briefly explored, ultimately leading to the conclusion that keeping the patient at the center is sine qua non of patient- and family-centered care.

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**Document 120**

Olsen, Molly L; Swetz, Keith M; Mueller, Paul S

**Ethical decision making with end-of-life care: palliative sedation and withholding or withdrawing life-sustaining treatments.**


**Abstract:** Palliative sedation (PS) is the use of medications to induce decreased or absent awareness in order to relieve otherwise intractable suffering at the end of life. Although uncommon, some patients undergoing aggressive symptom control measures still have severe suffering from underlying disease or therapy-related adverse effects. In these circumstances, use of PS is considered. Although the goal is to provide relief in an ethically acceptable way to the patient, family, and health care team, health care professionals often voice concerns whether such treatment is necessary or whether such treatment equates to physician-assisted suicide or euthanasia. In this review, we frame clinical scenarios in which PS may be considered, summarize the ethical underpinnings of the practice, and further differentiate PS from other forms of end-of-life care, including withholding and/or withdrawing life-sustaining therapy and physician-assisted suicide and euthanasia.

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**Document 121**

Alt-Epping, B; Simon, A; Nauck, F

**[Blood product substitution in palliative care]. = Substitution von Blutkomponenten in der Palliativversorgung.**

Deutsche medizinische Wochenschrift (1946) 2010 Oct; 135(42): 2083-7

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**Document 122**

Mack, Jennifer W; Paulk, M Elizabeth; Viswanath, Kasisomayajula; Prigerson, Holly G

**Racial disparities in the outcomes of communication on medical care received near death.**

Archives of internal medicine 2010 Sep 27; 170(17): 1533-40

**Abstract:** Black patients tend to receive more life-prolonging care at the end of life (EOL) than white patients. This study aimed to evaluate whether differences in patient-physician communication contribute to disparities in EOL care between black patients and white patients.

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European Association for Palliative Care (EAPC) framework for palliative sedation: an ethical discussion.

Abstract: ABSTRACT:

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Palliative cancer care ethics: principles and challenges in the Indian setting.

Abstract: Palliative cancer treatment is a system of care that seeks to relieve suffering in patients with progressive cancer. Given the intractable symptoms with which certain malignancies manifest, palliative care offers a practical approach towards improving the patient's quality of life. However, there are an array of ethical issues associated with this treatment strategy such as particular methods of pain relief, a reliable assessment of suffering, autonomy, and multi-specialist care. While these principles are important to increase and improve the network of palliative care, the resource-poor Indian environments present numerous barriers for these principles to be practically applied. As the infrastructure of comprehensive cancer centers develop, paralleled with an increase in training of palliative care professionals, significant improvements need to be made in order to elevate the status of palliative cancer care in India.

Stand by me: a volunteer's reflection on working on an academic palliative care unit in Germany.

Abstract: To relate personal experience and reflections on the tasks and role of a volunteer in an academic palliative care unit into the context of the English publications of 2009. We took a snapshot of the most recent publications as a way of placing the rather unique experiences of this German volunteer in an international context.

The pomegranate has many veils.

Abstract: For those of little or no means, leaving one's mark through financial assets, social connections, and human investment is difficult. Using secondary analysis of transcripts from face-to-face interviews with 33 terminally-ill patients from an outpatient clinic at a public hospital serving the disadvantaged in the southern United States, we examine the legacy participants wish to leave behind. As part of this process, participants assess life
circumstances to try and generate a legacy allowing them to remain personally relevant to loved ones after death. For the low-SES terminally ill persons in this study, the desire to leave a material legacy and the means to do so are not congruous. In the absence of economic resources to bequeath loved ones, participants describe their desire to leave loved ones some form of ethical currency to facilitate interactions with others and protect them against social marginalisation. We call this concept ethical capital. We then argue ethical capital is a way for disadvantaged people to find dignity and to affirm their lives.

Kress, H
[Terminal care in the form of sedation at the end of life. Current medical ethics recommendations and further need for discussion]. = Sterbehilfe in Form der Sedierung am Lebensende. Aktuelle medizinethische Empfehlungen und weiterer Diskussionsbedarf. Bundesgesundheitsblatt, Gesundheitsforschung, Gesundheitsschutz 2010 Sep; 53(9): 939-42

Gingell Epstein, Elizabeth
Moral obligations of nurses and physicians in neonatal end-of-life care. Nursing ethics 2010 Sep; 17(5): 577-89

Abstract: The aim of this study was to explore the obligations of nurses and physicians in providing end-of-life care. Nineteen nurses and 11 physicians from a single newborn intensive care unit participated. Using content analysis, an overarching obligation of creating the best possible experience for infants and parents was identified, within which two categories of obligations (decision making and the end of life itself) emerged. Obligations in decision making included talking to parents and timing withdrawal. End-of-life obligations included providing options, preparing parents, being with, advocating, creating peace and normalcy, and providing comfort. Nurses and physicians perceived obligations in both categories, although nurse obligations centered on the end of life while physician obligations focused on decision making. The findings demonstrate that, although the ultimate goal is shared by both disciplines, the paths to achieving that goal are often different. This has important implications for collaboration, communication, and improving the end of life.

Santos Salas, Anna; Cameron, Brenda L
Ethical openings in palliative home care practice. Nursing ethics 2010 Sep; 17(5): 655-65

Abstract: Understanding how a nurse acts in a particular situation reveals how nurses enact their ethics in day-to-day nursing. Our ethical frameworks assist us when we experience serious ethical dilemmas. Yet how a nurse responds in situations of daily practice is contingent upon all the presenting cues that build the current moment. In this article, we look at how a home care nurse responds to the ethical opening that arises when the nurse enters a person's home. We discuss how the home presents the nurse with knowledge that informs the provision of ethical nursing care. The analysis is based on findings from an interpretive research study in palliative home care in Canada. Through interpretive analysis of a nursing situation we delineate how the nurse engages with the whole and acts inside the moment. The analysis shows how home care nurses are ethically determined to engage with whatever is going on in a patient's home.
**Document 131**

Lacey, Judith; Sanderson, Christine

The oncologist's role in care of the dying cancer patient.

Cancer journal (Sudbury, Mass.) 2010 Sep-Oct; 16(5): 532-41

**Abstract:** Caring for dying patients is challenging for oncologists, but a crucial aspect of cancer care. It requires highly developed communication skills and an understanding of prognostication at the end of life, which can potentially be improved by training and use of appropriate tools. Psychosocial concerns are as important as physical symptoms. Specific strategies for supporting dying patients are evolving, including dignity therapy and other meaning-based therapies. Symptoms affecting dying patients' comfort, including pain, dyspnea, delirium, and terminal secretions, require different clinical management as death approaches. Equally important is the ability to discuss transitions in goals of care from cure to comfort and supporting families and patients to make wise decisions without feeling they have been abandoned. Involving a palliative care team supports both oncologists and patients by providing whole-person assessment and care and excellent symptom control and can offer bereavement services to follow up family members after death.

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**Document 132**

Cohen, Joachim; Chambaere, Kenneth; Bilsen, Johan; Houttekier, Dirk; Mortier, Freddy; Deliens, Luc

Influence of the metropolitan environment on end-of-life decisions: A population-based study of end-of-life decision-making in the Brussels metropolitan region and non-metropolitan Flanders.

Health & place 2010 Sep; 16(5): 784-93

**Abstract:** Research is beginning to show differences between end-of-life care in metropolitan and non-metropolitan areas. Using population-based post-mortem surveys this article compares medical end-of-life decisions in the Brussels metropolitan area and non-metropolitan Flanders (Belgium). In Brussels, administering lethal drugs without an explicit patient request occurred more often, intensification of symptom alleviation and non-treatment decisions less often, and end-of-life treatment was more often aimed at cure or life prolongation, than in non-metropolitan Flanders. This paper argues that these differences in end-of-life decisions are related to characteristics of the metropolitan environment and hence may also apply in other metropolitan regions worldwide. Specific approaches to end-of-life decisions in metropolitan areas need to be considered.

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**Document 133**

Vosit-Steller, Julie; White, Patricia; Barron, Anne-Marie; Gerzewitz, Diane; Morse, Allison

Enhancing end-of-life care with dignity: characterizing hospice nursing in Romania.

International journal of palliative nursing 2010 Sep; 16(9): 459-64

**Abstract:** The purpose of this research was to characterize the nursing actions practiced by Romanian nurses affiliated with Hospices of Hope that promote dignified dying and explore needs to promote a more dignified death.

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**Document 134**

Seno, Virginia L

Being-with dying: authenticity in end-of-life encounters.

The American journal of hospice & palliative care 2010 Sep; 27(6): 377-86

**Abstract:** Families and their dying members have notably unmet needs. This is in large part due to health professionals being unprepared to be authentic (emotionally appropriate, purposive, and responsible) in end-of-life encounters. Martin Heidegger's interpretive phenomenology informed this study, providing background, structures, language, and metaphors to interpret narratives for patterns of authentic being-with dying among nurses who attend to dying. Semistructured interviews elicited tacit knowledge imbedded in the experiences of those nurses and
showed how they comfort themselves in end-of-life situations. Patterns emerged in a presence of authentic being-with-dying, which assisted persons in their transitions toward a peaceful death. Patterns are explicated in a 5-point framework, which paralleled Heidegger's structures of authentic being-toward-death.

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Document 135
Blagbrough, Joanne

**Importance of sexual needs assessment in palliative care.**
Nursing standard (Royal College of Nursing (Great Britain) : 1987) 2010 Sep 1-7; 24(52): 35-9

**Abstract:** Sexuality is a fundamental aspect of being human. Guidance states that to support and improve the lives of adults with life-limiting illness, health professionals must address care in the social, psychological, spiritual and physical domains, yet no mention is made of the sexual domain. Palliative care aims to be holistic yet evidence suggests that sexuality is often overlooked when assessing care needs. This literature review will identify the issues that prevent sexual needs assessment in palliative care.

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Document 136
Mahon, Margaret M

**Clinical decision making in palliative care and end of life care.**
The Nursing clinics of North America 2010 Sep; 45(3): 345-62

**Abstract:** Clinical decision making involves a consideration of multiple factors; clinical options are constructed based on the objective clinical data and evidence-based standards. Technologic advances have led not only to life saving interventions, but also to the use of these technologies when benefit to the patient was unclear or unexamined. The cases of Karen Quinlan, Nancy Cruzan, and Terri Schiavo provide a framework for examining the evolution of clinical decision making, including when to use or not to use technologies such as ventilators and artificial nutrition and hydration, and the role of specific questions in the process. Advance directives are a means to convey patient preferences, however, in the absence of advance directives, skilled questioning can elicit patient preferences. Nurses' roles in clinical decision making are often nebulous but can be enhanced by understanding these interrelated processes, as well as by knowing the policies and procedures of their institutions.

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Document 137
Braswell, Katelyn; Bolton, Willburn; Hundley, Grace; Rutecki, Gregory W.

**End-of-life care in the long-term cancer survivor**
Ethics and Medicine 2010 Fall; 26(3): 143-146

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Document 138
Kaebnick, Gregory E

**Public and private.**
The Hastings Center report 2010 Sep-Oct; 40(5): 2

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Document 139
Ganzini, Linda
Strange deathbedfellows.
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Document 140
Campbell, Courtney S; Cox, Jessica C
Hospice and physician-assisted death: collaboration, compliance, and complicity.
Abstract: Although the overwhelming majority of terminally ill patients in Oregon who seek a physician's aid in dying are enrolled in hospice programs, hospices do not take a major role in this practice. An examination of fifty-five Oregon hospices reveals that both legal and moral questions prevent hospices from collaborating fully with physician-assisted death.
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Document 141
Hartwick, Michael; Jones, Gwynne
Resolving disagreement during end of life care in the critical care unit: the case for communication not arbitration.
Clinical and investigative medicine. Médecine clinique et experimentale 2010 August 1; 33(4): E219-22
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Document 142
Choong, Karen; Cupido, Cynthia; Nelson, Erin; Arnold, Donald M; Burns, Karen; Cook, Deborah; Meade, Maureen; ACCADEMY
A framework for resolving disagreement during end of life care in the critical care unit.
Clinical and investigative medicine. Médecine clinique et experimentale 2010 August 1; 33(4): E240-53
Abstract: End-of-life decisions regarding the administration, withdrawal or withholding of life-sustaining therapy in the critical care setting can be challenging. Disagreements between health care providers and family members occur, especially when families believe strongly in preserving life, and physicians are resistant to providing medically "futile" care. Such disagreements can cause tension and moral distress among families and clinicians.
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Document 143
Gristina, G R; SIAARTI Study Group on Bioethics
Comments by the SIAARTI study group on bioethics on the review "end-of-life care is still a challenge for Italy".
Minerva anestesiologica 2010 Aug; 76(8): 668-9; author reply 673-4
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Document 144

Ethical challenges in the provision of end-of-life care in Norwegian nursing homes.


Abstract: As in other Western countries, most Norwegian nursing home patients are suffering from multi-pathological conditions and a large majority of them will die in the nursing home. End-of-life care represents many challenges, and it is a widespread concern that several nursing homes lack both resources and competence to ensure good quality care. This article examines the types and prevalence of ethical challenges in end-of-life care as nursing home staff consider them, as well as what they believe can help them to better cope with the ethical challenges. It is based on a national survey probing Norwegian nursing homes' end-of-life care at the ward level conducted in 2007. 664 respondents from 364 nursing homes answered the questionnaire, representing 68% of the patients and 76% of the nursing home sample. Inadequate care due to lack of resources and breaches of the patient's autonomy and integrity were the ethical challenges reported most often. Conflicts with the next of kin regarding nursing care and termination of life-prolonging treatment were reported more seldom. However, when asking the respondents to outline one of the most recent ethical dilemmas they had encountered, the majority of the respondents described ethical dilemmas concerning limitation of life-prolonging treatment, often mixed with disagreements between the wish of the family and that of the patient, or between the wish of the next of kin and what the staff consider to be right. Ethical dilemmas associated with breaches of the patient's autonomy and integrity were also thoroughly described. According to the staff, better ethical knowledge along with more time to reflect on ethical dilemmas were the initiatives most desired to improve the staff's way of handling ethical challenges. Furthermore, to have an opportunity to consult with a person holding ethical competence was emphasised by more than half of the respondents.

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Document 145

Decision making by parents of children with incurable cancer who opt for enrollment on a phase I trial compared with choosing a do not resuscitate/terminal care option.


Abstract: PURPOSE: Parents of children with incurable cancer make complex and difficult decisions about remaining treatment options. We compared the self-reported rationale, good parent definition, and desired clinical staff behaviors of parents who recently decided for phase I (P1) chemotherapy with parents who chose a do not resuscitate (DNR) or terminal care (TC) option. PATIENTS AND METHODS: Sixty-two parents of 58 children were asked for the basis of their decision, their definition of a good parent, and what staff behaviors supported their good parent role. After semantic content analysis, results were compared in the P1 versus DNR/TC groups. These categories were mutually exclusive but did not necessarily represent an either/or decision. RESULTS: Thirty-one decisions were for P1 chemotherapy and 27 for DNR/TC. Median survival time after study enrollment was greater in the P1 group (0.4 v 0.1 years). Most P1 group parents reported having felt compelled to continue cancer-directed therapy (71% v 7%), whereas those who opted for DNR/TC cited quality of life (QOL; 74% v 3%) and patient wishes (67% v 13%). Decision factors common to both groups were medical facts, doing right, and others' opinions. Both groups believed that a good parent did right, provided support and presence, and sacrificed for the child. The groups desired similar support from clinicians and expressed gratitude. CONCLUSION: Despite similar definitions of a good parent and desired staff behaviors, parents in the P1 group reported having felt compelled to continue cancer-directed therapy, whereas QOL and patient wishes were emphasized in decisions for DNR/TC.

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Document 146

End-of-life decision making in the intensive care unit.

American journal of respiratory and critical care medicine 2010 Jul 1; 182(1): 6-11

Abstract: Increasingly in the United States and other countries, medical decisions, including those at the end of life, are made using a shared decision-making model. Under this model, physicians and other clinicians help patients clarify their values and reach consensus about treatment courses consistent with them. Because most critically ill
patients are decisionally impaired, family members and other surrogates must make end-of-life decisions for them, ideally in accord with a substituted judgment standard. Physicians generally make decisions for patients who lack families or other surrogates and have no advance directives, based on a best interests standard and occasionally in consultation with other physicians or with review by a hospital ethics committee. End-of-life decisions for patients with surrogates usually are made at family conferences, the functioning of which can be improved by several methods that have been demonstrated to improve communications. Facilitative ethics consultations can be helpful in resolving conflicts when physicians and families disagree in end-of-life decisions. Ethics committees actually are allowed to make such decisions in one state when disagreements cannot be resolved otherwise.

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**Document 147**

Luce, John M

**End-of-life decision making in the intensive care unit.**

American journal of respiratory and critical care medicine 2010 Jul 1; 182(1): 6-11

**Abstract:** Increasingly in the United States and other countries, medical decisions, including those at the end of life, are made using a shared decision-making model. Under this model, physicians and other clinicians help patients clarify their values and reach consensus about treatment courses consistent with them. Because most critically ill patients are decisionally impaired, family members and other surrogates must make end-of-life decisions for them, ideally in accord with a substituted judgment standard. Physicians generally make decisions for patients who lack families or other surrogates and have no advance directives, based on a best interests standard and occasionally in consultation with other physicians or with review by a hospital ethics committee. End-of-life decisions for patients with surrogates usually are made at family conferences, the functioning of which can be improved by several methods that have been demonstrated to improve communications. Facilitative ethics consultations can be helpful in resolving conflicts when physicians and families disagree in end-of-life decisions. Ethics committees actually are allowed to make such decisions in one state when disagreements cannot be resolved otherwise.

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**Document 148**

Penner, Leigh; Cantor, Rabbi Mollie; Siegel, Linda

**Joseph's wishes: ethical decision-making in Duchenne muscular dystrophy.**


**Abstract:** The death of a child is an uncommon occurrence and can be difficult for families to accept. Attempts by the healthcare team to discuss end-of-life issues can be so upsetting to families that they refuse to participate in the discussion. Even with diseases where an early death can be anticipated, such as Duchenne muscular dystrophy, the family is often reluctant to discuss end-of-life issues when the patient is relatively healthy, preferring to focus on the current health issues. In this article we discuss what happens when there are disagreements between the patient and family and the needs of both must be taken into consideration.

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**Document 149**

Virt, Günter; Hunstorfer, Karl

**[Ethical discussion of palliative sedation]. = Ethische Überlegungen zur palliativen Sedierung.**

Wiener medizinische Wochenschrift (1946) 2010 Jul; 160(13-14): 331-7

**Abstract:** This article discusses ethical implications of palliative sedation at the end of life. Terminal or palliative sedation, like other denominations are discussed in literature, which invite to a profound discussion. From an ethical point of view, terminal or palliative sedation seems to be a way out when in intolerable suffering or situations without prospects, the demand for euthanasia arises. The possibility to use palliative sedation for effective control of otherwise refractory suffering provokes the question if it even can be used with the intention to hasten death. This has led to ethical concerns on the use and limits of sedation. Therefore it seems to be necessary to elaborate clear guidelines in handling sedation in end-of-life care to prevent misuse. The contribution of ethical considerations can
clarify the position and use of palliative sedation.

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### Document 150

Wiesinger, Karlheinz; Christof Müller-Busch, H

*Will, may, should, can, must: The limits of care and palliation. = Wollen, dürfen, sollen, können, müssen. Die Grenzen von Kuration und Palliation.*

Wiener medizinische Wochenschrift (1946) 2010 Jul; 160(13-14): 343-8

**Abstract:** Informed consent is the condition for treating a patient, in curative and palliative settings. If, due to the medical situation, a valid consent cannot be acquired a substituted judgement based on information about the patients preferences will be applied. Accordingly the mobile palliative team of Caritas Socialis requires that patients are informed about their disease condition and agree to palliative measures. The team asks for clear communication about end of life situations, death and dying, which is sometimes difficult for relatives and patients. Sometimes defense mechanisms appear to deny the true situation in order to cope with the disease. The case report shows an example of a particular problematic challenge to combine palliative ideas with impossible curative hopes. An open discussion tries to clarify positions and seeks for future solutions.

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### Document 151

Longenecker, Paul D

*The ethical balancing act of hospice care.*


**Abstract:** In providing hospice care, clinicians are confronted with ethical challenges on a daily basis involving their patients and families, their personal values and beliefs, and organizational practices. Being able to objectively understand these ethical challenges and having a plan of action to address is essential in effectively fulfilling the role of being a hospice professional.

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### Document 152

Stilos, Kalli; Daines, Patricia

*Guiding decisions about end-of-life care: navigating the nursing role.*

CANNT journal = Journal ACITN 2010 Jul-Sep; 20(3): 56-7

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### Document 153

Zamperetti, N; Piccinni, P

*End of life in the Intensive Care Unit.*

Minerva anestesiologica 2010 Jul; 76(7): 541-7

**Abstract:** A bio-social revolution has been prompted by the capacity of artificial organ support technology to effectively sustain and/or replace many of the functions of vital organs. The consequent possibility of manipulating the dying process has generated many problems, which range from the necessity of rationing scarce and expensive resources to the definition of optimal care for dying people and the necessity of redefining death itself. In all of these situations, facts and values are strictly interconnected, and actions should be accompanied by careful bioethical reflection. In this text, we will briefly explore these issues in an attempt to illustrate the main problems related to the management of end-of-life care in the intensive care environment. We also present the protocol we use to make and implement difficult end-of-life decisions in our intensive care unit.
Document 154
Klick, Jeffrey C; Hauer, Julie

**Pediatric palliative care.**
Current problems in pediatric and adolescent health care 2010 Jul; 40(6): 120-51

**Abstract:** Palliative care has always been a part of the care of children. It includes any intervention that focuses on relieving suffering, slowing the progression of disease, and improving quality of life at any stage of disease. In addition, for even the child with the most unpredictable disease, there are predictable times in this child's life when the child, family, and care team will be suffering in ways that can be mitigated by specific interventions. Rather than defining pediatric palliative care in terms of a patient base, severity of disease, or even a general philosophy of care, palliative care can best be understood as a specific set of tasks directed at mitigating suffering. By understanding these tasks; learning to identify predictable times and settings of suffering; and learning to collaborate with multidisciplinary specialists, use communication skills, and identify clinical resources, the pediatrician can more effectively support children with life-threatening illnesses and their families. In this article, we define palliative care as a focus of care integrated in all phases of life and as a set of interventions aimed at easing suffering associated with life-threatening conditions. We detail an approach to these interventions and discuss how they can be implemented by the pediatrician with the support of specialists in hospice and palliative medicine. We discuss common and predictable times of suffering when these interventions become effective ways to treat suffering and improve quality of life. Finally, we discuss those situations that pediatricians most commonly and intensely interface with palliative care-the care of the child with complex, chronic conditions and severe neurologic impairment (SNI).

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Document 155
Johnson, Rebecca W; Newby, L Kristin; Granger, Christopher B; Cook, Wendy A; Peterson, Eric D; Echols, Melvin; Bride, Wanda; Granger, Bradi B

**Differences in level of care at the end of life according to race.**

**Abstract:** Tailoring care for patients and their families at the end of life is important.

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Document 156
Levin, Tomer T; Moreno, Beatriz; Silvester, William; Kissane, David W

**End-of-life communication in the intensive care unit.**

**Abstract:** Because one in five Americans die in the intensive care unit (ICU), the potential role of palliative care is considerable. End-of-life (EOL) communication is essential for the implementation of ICU palliative care. The objective of this review was to summarize current research and recommendations for ICU EOL communication.

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Document 157
Krishna, Lalit

**Consent in terminal sedation.**
Indian journal of medical ethics 2010 Jul-Sep; 7(3): 161-4

**Abstract:** For the majority of patients at the end of life, their symptoms can be relieved through good palliative care. However, for an unfortunate few, these symptoms become intractable despite the best holistic interventions and in
such cases terminal sedation is considered. The use of this intervention remains fraught with controversy,
particularly around the subject of consent. A clinical scenario is used to propose that under such circumstances,
given the physical and psychological stress to which these patients are subject, it is neither useful nor meaningful to
ask for the patient's informed consent. Instead, physicians caring for such patients should act in the patient's best
interests, in accordance with the Best Interest Principle, to alleviate such suffering.

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**Document 158**

Dreyer, A; Førde, R; Nortvedt, P

**Life-prolonging treatment in nursing homes: how do physicians and nurses describe and justify their own practice?**

Journal of medical ethics 2010 Jul; 36(7): 396-400

**Abstract:** Making the right decisions, while simultaneously showing respect for patient autonomy, represents a great
challenge to nursing home staff in the issues of life-prolonging treatment, hydration, nutrition and hospitalisation to
dying patents in end-of-life.

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**Document 159**

Downar, James; Sibbald, Robert; Lazar, Neil M

**Ethical considerations for classifying patients as 'palliative' when calculating Hospital Standardised Mortality
Ratios.**


**Abstract:** The Hospital Standardised Mortality Ratio (HSMR) is a commonly used measure of hospital mortality that
is standardised for age, comorbidities and other factors. By tradition, this statistic has always excluded patients
classified as 'palliative'. The HSMR has never been validated as a reliable measure of quality of care, and it can be
very hard to interpret, partly due to difficulties with defining and applying the term 'palliative'. In this paper, we review
the Canadian experience with the palliative status flag, and explain why it is so difficult to define and apply
consistently. We also highlight some potential concerns about clinicians labelling inpatients as 'palliative' during their
admission. Finally, we propose an organisational ethics framework, and six specific suggestions for hospitals to use
when publishing statistics such as the HSMR.

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**Document 160**

Izumi, Shigeko

**Ethical practice in end-of-life care in Japan.**

Nursing ethics 2010 Jul; 17(4): 457-68

**Abstract:** Nurses are obliged to provide quality nursing care that meets the ethical standards of their profession.
However, clear descriptions of ethical practice are largely missing in the literature. Qualitative research using a
phenomenological approach was conducted to explicate ethical nursing practice in Japanese end-of-life care settings
and to discover how ethical practices unfold in clinical situations. Two paradigm cases and contrasting narratives of
memorable end-of-life care from 32 Japanese nurses were used to reveal four levels of ethical practice: ethical,
distressed, uncertain, and unethical. Having the ability to actualize, justify, and recognize what is the good and/or
right differentiated between these levels of ethical practice, empirical descriptions of which are given, followed by
discussion of how nurses gain the skilled knowledge necessary for ethical practice.

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**Document 161**
Meg, Zomorodi; Mary R. Lynn

**Instrument development measuring critical care nurses' attitudes and behaviors with end-of-life care.**

Nursing research 2010 Jul-Aug; 59(4): 234-40

**Abstract:** BACKGROUND: Although critical care nurses are expected to focus on providing life-sustaining measures, many intensive care patients actually receive end-of-life care. OBJECTIVES: The aim of this study was to develop an instrument to measure nursing attitudes and behaviors regarding end-of-life care. METHOD: Phase 1 was focused on item development from a content analysis of the literature and qualitative interviews of critical care nurses. Phase 2 consisted of content validity assessment and pilot testing. Phase 3 included field testing, factor analysis, and reliability estimation. RESULTS: The Values of Intensive Care Nurses for End-of-Life (n = 695) was found to have four factors: Self-appraisal, Appraisal of Others, Emotional Strain, and Moral Distress. Reliability estimates (\(\alpha\)) were acceptable at .59-.78, but the interitem range (.12-.78) was wider than desirable. Test-retest reliability was deemed adequate based on Pearson's correlations (.68-.81) and intraclass correlation coefficients (.65-.79) but less so when considering \(kappa\) (.05-.30). The Behaviors of Intensive Care Nurses for End-of-Life (n = 682) was found to have two factors: Communication and Nursing Tasks. Reliability estimates were adequate when considering internal consistency (\(\alpha\) = .67 and .78, respectively), item total correlations (.30-.61), and test-retest as judged by Pearson's and intraclass correlations (.77-.81) but not when \(kappa\) was considered (.02-.40). The interitem correlations (.20-.35) were also lower than desirable. DISCUSSION: Both the Values of Intensive Care Nurses for End-of-Life and the Behaviors of Intensive Care Nurses for End-of-Life were found to have conceptually linked factors and acceptable internal consistency estimates (\(\alpha\)). However, test-retest estimates were inconsistent, suggesting that further work needs to be done on the stability of these instruments.

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Brown-Saltzman, Katherine; Upadhya, Devesh; Larner, Lyle; Wenger, Neil S

**An intervention to improve respiratory therapists' comfort with end-of-life care.**

Respiratory care 2010 Jul; 55(7): 858-65

**Abstract:** BACKGROUND: Respiratory therapists (RTs) are often involved in treating seriously ill and dying patients, but receive little instruction in end-of-life care. Prompted by several difficult cases, we developed an interdisciplinary program to introduce practicing RTs to ethical and end-of-life issues, and evaluated the program with a dedicated survey instrument. METHODS: A convenience sample of RTs from a university hospital and nearby community hospitals participated in a one-day interactive program, in 2005 (n = 49) and in 2008 (n = 36), that included role-play and didactic components. The questionnaire completed before and after the program included scales on comfort with end-of-life care and role in end-of-life care, and knowledge indices. RESULTS: Nearly all the RTs had recently encountered end-of-life situations, yet most had not received dedicated training and felt ill-prepared to deal with these situations; one third reported distress related to withdrawal of treatment. The 78 participants who completed both the before and after surveys had increased comfort with end-of-life care (P < .001) and their perception of their role in end-of-life care (P < .001). Knowledge about end-of-life care also increased (P < .001). CONCLUSIONS: A one-day interactive educational intervention can improve short-term RT comfort and role perception concerning end-of-life care. Evaluation of longer-term clinical outcomes and implementation in other venues is needed.

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Willms, David C

**Finding comfort in end-of-life care.**

Respiratory care 2010 Jul; 55(7): 949

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Soreide, J A

**Palliative surgical care.**
Document 165
Schicktanz, Silke; Raz, Aviad; Shalev, Carmel
The cultural context of end-of-life ethics: a comparison of Germany and Israel.

Document 166
Congedo, M; Causarano, R I; Alberti, F; Bonito, V; Borghi, L; Colombi, L; Defanti, C A; Marcello, N; Porteri, C; Pucci, E; Tarquini, D; Tettamanti, M; Tiezzi, A; Tiraboschi, P; Gasparini, M;
Bioethics and Palliative Care in Neurology Study Group of Italian Society of Neurology
Ethical issues in end of life treatments for patients with dementia.
European journal of neurology : the official journal of the European Federation of Neurological Societies 2010 Jun 1; 17(6): 774-9
Abstract: Dementia is a terminal disease, associated with great suffering and difficult decisions in the severe stage. The decision-making process is characterized by uncertainty because of lack of scientific evidence in treatments and by the need to reconcile conflicting points of view. In intercurrent diseases, aggressive interventions are used without consideration of its futility; in comparison with cancer, several consequences of physicians' attitude not to consider dementia as a terminal disease have been reported, especially concerning pain relief. Lack of evidence of artificial nutrition and hydration effectiveness makes advance care planning relevant.

Document 167
de Kort, Susanne J; Pols, Jeannette; Koedoot, Nelleke; Willems, Dick L
Understanding palliative cancer chemotherapy: about shared decisions and shared trajectories.
Abstract: Most models of patient-physician communication take decision-making as a central concept. However, we found that often the treatment course of metastatic cancer patients is not easy to describe in straightforward terms used in decision-making models but is instead frequently more erratic. Our aim was to analyse these processes as trajectories. We used a longitudinal case study of 13 patients with metastatic colorectal and pancreatic cancer for whom palliative chemotherapy was a treatment option, and analysed 65 semi-structured interviews. We analysed three characteristics of the treatment course that contributed to the 'erraticness' of the course: (1) The treatment (with or without chemotherapy) contained many options; (2) these options were not stable entities to be decided upon, but changed identity over the course of treatment, and (3) contrary to the closure (option X means no option Y, Z, etc.) a decision implies, the treatment course was a continuous process in which options instead remained open. When the treatment course is characterised by these many and changeable options that do not result in closure, the shared decision-making model should take these into account. More attention needs to be paid to the erratic character of the process in which the doctor has to provide continuous information that is related to the changing situation of the patient; also, flexibility in dealing with protocols is warranted, as is vigilance about the overall direction of the process.

Document 168
Storme, Laurent; de Mézerac, Isabelle
[Dealing with parents facing imminent death of their neonate: introducing palliative care in maternity wards}
and neonatal intensive care units]. = L'accompagnement des parents face à une mort annoncée en périnatalité: pour l'introduction d'une démarche de soins palliatifs en maternité et en néo-natologie.


Abstract: Following antenatal diagnosis of a lethal disorder, some parents are so overwhelmed by grief that therapeutic abortion is seen as the least traumatic option. However, the impending death and anticipated mourning create a particularly complex emotional situation. When faced with such dramatic circumstances, some parents seek to restore meaning to their parenthood by accompanying their baby through to the end of its life. Methods derived from hospice care may be appropriate in such situations, considering the unborn child as "a living being among the living ", pregnancy as the first chapter of every life, and death as a natural process. This approach, which may be adopted in maternity wards and neonatal intensive care units, requires the medical team to provide consistent information to the parents and to ensure their close involvement. These new parental demands must be clearly understood if they are to be met as effectively as possible.

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developed by leaders in the field who examined other national and international standards with the intent to promote consistent, accessible, comprehensive, optimal palliative care through the health care spectrum. Within the guidelines there are eight domains to the provision of palliative care. This article focuses on the last, but very significant Domain 8—Ethical and Legal Aspects of Care.

Document 173
Kirby, Jeffrey
Accessing the ethics of complex health care practices: would a “domains of ethics analysis” approach help?
HEC forum: an interdisciplinary journal on hospitals' ethical and legal issues 2010 Jun; 22(2): 133-43
Abstract: This paper explores how using a "domains of ethics analysis" approach might constructively contribute to an enhanced understanding (among those without specialized ethics training) of ethically-complex health care practices through the consideration of one such sample practice, i.e., deep and continuous palliative sedation (DCPS). For this purpose, I select four sample ethics domains (from a variety of possible relevant domains) for use in the consideration of this practice, i.e., autonomous choice, motives, actions and consequences. These particular domains were chosen because of their relevance to the analysis of DCPS and their relative ease of access to those without ethics training. The analysis demonstrates that such an approach could facilitate the emergence of accessible arguments and discussion points that could enhance the understanding and appreciation of this and other health care practices with strong ethics dimensions.

Document 174
Floriani, Ciro Augusto; Schramm, Ferman Roland
How might Levinas’ concept of the other’s priority and Derrida’s unconditional hospitality contribute to the philosophy of the modern hospice movement?
Palliative & supportive care 2010 Jun; 8(2): 215-20
Abstract: Hospitality is commonly referred as one of the meanings of hospes, the Latin word which is also the root of hospice. This article explores the semantics of the word hospice - the seal of identity of modern hospice movement - and attempts to integrate the meaning of hospitality into the modern hospice movement, understood as unconditional reception. Therefore, the article analyzes the concept of unconditional hospitality, developed by Jacques Derrida and that of ethical responsibility proposed by Emmanuel Levinas based on the phenomenological experience of the other. From this point of view, these two concepts tie in with the meaning of hospice, bringing substantial grounding elements to the hospice movement for the construction of a protective ethos.

Document 175
Yancu, Cécile N; Farmer, Deborah F; Leahman, Dee
Barriers to hospice use and palliative care services use by African American adults.
Abstract: This study explored the reasons for low levels of hospice participation by African Americans. METHODS: Data about attitudes toward dying and death, advanced directives, and barriers to using hospice services were collected from 314 adults attending 11 diversely populated churches in North Carolina. RESULTS: Almost all participants indicated (91%) willingness to use hospice, particularly if the hospice team were diverse (77%). Most are without a living will (72%) or health care power of attorney (81%); approximately half (54%) have shared final care wishes. Discussion: Despite evidence of a willingness to use hospice, African Americans were unlikely to complete advanced directives or share final care wishes. However, many were more likely to use hospice if the care team were diverse suggesting the importance of culture.
Document 176
Chun, Erin Diviney; Rodgers, Phillip E; Vitale, Caroline A; Collins, Curtis D; Malani, Preeti N
Antimicrobial use among patients receiving palliative care consultation.
Abstract: We sought to characterize antimicrobial use among patients receiving palliative care consultation.

Document 177
Baumrucker, Steven J; Sheldon, Joanne E; Stolick, Matt; Oertli, Karrie A; Harrington, Dianne; VandeKieft, Gregg; Morris, Gerald M
End-of-life care when the state is the guardian.

Document 178
Thoms, Andrew
Ethical and legal issues in end-of-life care.
Abstract: The doctor has a responsibility to develop and maintain an effective approach to ethical decision making and the skills to implement the correct moral action. At the heart of this process is the experience and knowledge of particular conditions and their outcomes, alongside excellence in communication skills and working with colleagues.

Document 179
Piva, Jefferson; Lago, Patrícia; Othero, Jairo; Garcia, Pedro Celiny; Fiori, Renato; Fiori, Humberto; Borges, Luiz Alexandre; Dias, Fernando S
Evaluating end of life practices in ten Brazilian paediatric and adult intensive care units.
Abstract: To evaluate the modes of death and treatment offered in the last 24 h of life to patients dying in 10 Brazilian intensive care units (ICUs) over a period of 2 years.

Document 180
Kobusch, Dorit
[Together one is less alone] = Zusammen ist man weniger allein.
Pflege Zeitschrift 2010 Jun; 63(6): 321

Document 181
Haarhaus, Friedrich
[Reflections on terminal care from the theological viewpoint: the dignity of man--during life and in dying] =
Pflege Zeitschrift 2010 Jun; 63(6): 336-7
Georgetown users check Georgetown Journal Finder for access to full text

Gaulke, Katrin; Rose, Veronika
Pflege Zeitschrift 2010 Jun; 63(6): 347-9
Georgetown users check Georgetown Journal Finder for access to full text

Kodner, Ira J
If an operation can't cure you, what can I do?
Georgetown users check Georgetown Journal Finder for access to full text

Scaduto, Cecelia Marie
Terminal sedation can be licit
Ethics and Medics 2010 June; 35(6): 3-4
Georgetown users check Georgetown Journal Finder for access to full text

http://www.ncbcenter.org/NetCommunity/Page.aspx?pid=322 (link may be outdated)

West, Dave; Lomas, Clare; Clover, Ben
Last offices neglected in over half of hospital deaths.
Nursing times 2010 May 11-17; 106(18): 1
Georgetown users check Georgetown Journal Finder for access to full text

Periyakoil, Vyjeyanthi S; Noda, Arthur M; Kraemer, Helena Chmura
Assessment of factors influencing preservation of dignity at life's end: creation and the cross-cultural validation of the preservation of dignity card-sort tool.
Journal of palliative medicine 2010 May; 13(5): 495-500
Abstract: BACKGROUND: Preserving patient dignity is a sentinel premise of palliative care. This study was conducted to gain a better understanding of factors influencing preservation of dignity in the last chapter of life. METHODS: We conducted an open-ended written survey of 100 multidisciplinary providers (69% response rate) and responses were categorized to identify 2 main themes, 5 subthemes, and 10 individual factors that were used to create the preservation of dignity card-sort tool (p-DCT). The 10-item rank order tool was administered to a cohort of community dwelling Filipino Americans (n = 140, age mean = 61.3, 45% male and 55% female). A Spearman
A correlation matrix was constructed for all the 10 individual factors as well as the themes and subthemes based on the data generated by the subjects. RESULTS: The individual factors were minimally correlated with each other indicating that each factor was an independent stand-alone factor. The median, 25th and 75th percentile ranks were calculated and "s/he has self-respect" (intrinsic theme, self-esteem subtheme) emerged as the most important factor (mean rank 3.0 and median rank 2.0) followed by "others treat her/him with respect" (extrinsic theme, respect subtheme) with a mean rank = 3.6 and median = 3.0. CONCLUSION: The p-DCT is a simple, rank order card-sort tool that may help clinicians identify patients' perceptions of key factors influencing the preservation of their dignity in the last chapter of life.

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**Document 187**

Rady, Mohamed Y; Verheijde, Joseph L

**Continuous deep sedation until death: palliation or physician-assisted death?**

The American journal of hospice & palliative care 2010 May; 27(3): 205-14

**Abstract:** Published literature has not discerned end-of-life palliative versus life-shortening effects of pharmacologically maintaining continuous deep sedation until death (i.e., dying in deep sleep) compared with common sedation practices relieving distress in the final conscious phase of dying. Continuous deep sedation predictably suppresses brainstem vital centers and shortens life. Continuous deep sedation remains controversial as palliation for existential suffering and in elective death requests by discontinuation of chronic ventilation or circulatory support with mechanical devices. Continuous deep sedation contravenes the double-effect principle because: (1) it induces permanent coma (intent of action) for the contingency relief of suffering and for social isolation (desired outcomes) and (2) because of its predictable and proportional life-shortening effect. Continuous deep sedation should be distinguished from common sedation practices for palliation and characterized instead as physician-assisted death.

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**Document 188**

Moriette, G; Rameix, S; Azria, E; Fournié, A; Andrini, P; Caeymaex, L; Dageville, C; Gold, F; Kuhn, P; Storme, L; Siméoni, U; Groupe de réflexion sur les aspects éthiques de la périnatologie


Archives de pédiatrie : organe officiel de la Société française de pédiatrie 2010 May; 17(5): 527-39

**Abstract:** In the first part of this work, the outcome following very premature birth was assessed. This enabled a gray zone to be defined, with inherent major prognostic uncertainty. In France today, the gray zone corresponds to deliveries occurring at 24 and 25 weeks of postmenstrual age. The management of births occurring below and above the gray zone was described. Withholding intensive care at birth for babies born below or within the gray zone does not mean withholding care but rather providing palliative care to prevent pain and suffering during the time period preceding death. Given the high level of uncertainty, making good decisions within the gray zone is problematic. Decisions should be based on the infant's best interests. Decisions should be reached with the parents, who are entitled to receive clear and comprehensive information. Possible decisions to withhold intensive care should be made following the procedures described in the French law of April 2005. Guidelines, based on gestational age and the other prognostic elements, are proposed to the parents before birth. They are applied in an individualized fashion, in order to take into account the individual features of each case. At 25 weeks, resuscitation and/or full intensive care are usually proposed, unless unfavorable factors, such as severe growth restriction, are associated. A senior neonatologist will attend the delivery and will make decisions based on both the baby's condition at birth and the parents' wishes. At 24 weeks, in the absence of unfavorable associated factors, the parents' wishes should be followed in deciding between initiating full intensive care or palliative care. Below 24 weeks, palliative care is the only option to be offered in France at the present time.

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Moriette, G; Rameix, S; Azria, E; Fournié, A; Andrini, P; Caeymaex, L; Dageville, C; Gold, F; Kuhn, P; Storme, L; Siméoni, U; Groupe de réflexion sur les aspects éthiques de la périnatologie


Archives de pédiatrie : organe officiel de la Sociéte française de pédiatrie 2010 May; 17(5): 518­26

Abstract: With very preterm deliveries, the decision to institute intensive care, or, alternatively, to start palliative care and let the baby die, is extremely difficult, and involves complex ethical issues. The introduction of intensive care may result in long-term survival of many infants without severe disabilities, but it may also result in the survival of severely disabled infants. Conversely, the decision to withhold resuscitation and/or intensive care at birth, which is an option at the margin of viability, implies allowing babies to die, although some of them would have developed normally if they had received resuscitation and/or intensive care. Withholding intensive care at birth does not mean withholding care but rather providing palliative care to prevent pain and suffering during the time period preceding death. The likelihood of survival without significant disabilities decreases as gestational age at birth decreases. In addition to gestational age, other factors greatly influence the prognosis. Indeed, for a given gestational age, higher birth weight, singleton birth, female sex, exposure to prenatal corticosteroids, and birth in a tertiary center are favorable factors. Considering gestational age, there is a gray zone that corresponds to major prognostic uncertainty and therefore to a major problem in making a "good" decision. In France today, the gray zone corresponds to deliveries at 24 and 25 weeks of postmenstrual age. In general, babies born above the gray zone (26 weeks of postmenstrual age and later) should receive resuscitation and/or full intensive care. Below 24 weeks, palliative care is the only option offered in France at the present time. Decisions within the gray zone will be addressed in the 2nd part of this work.

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Paganini, Maria Cristina;

Nurses' autonomy and end-of-life decision making.

Nursing ethics 2010 May ; 17(3): 285­7

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Berger, Jeffrey T

Rethinking guidelines for the use of palliative sedation.

The Hastings Center report 2010 May-Jun; 40(3): 32­8

Abstract: Current guidelines treat palliative sedation to unconsciousness as an effective medical treatment for terminally ill patients who need relief from severe symptoms, yet also restrict its use in ways that are extraordinary for medical treatments. A closer look at the kinds of cases in which palliative sedation is used suggests a way of adjusting the guidelines to resolve this seeming contradiction.

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Laabs, Carolyn A.

Nurses and care of patients at the end of life: on the ANA revised position statement

Linacre Quarterly 2010 May; 77(2): 168-174

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Document 193
Calhoun, Byron D.
**Compassionate and comprehensive care for families with lethal prenatal diagnosis**
Linacre Quarterly 2010 May; 77(2): 147-156

Document 194
Karlsson, Margareta; Roxberg, Asa; da Silva, António Barbosa; Berggren, Ingela
**Community nurses' experiences of ethical dilemmas in palliative care: a Swedish study.**
International journal of palliative nursing 2010 May; 16(5): 224-31

Document 195
McCloskey, Sharon; Taggart, Laurence
**How much compassion have I left? An exploration of occupational stress among children's palliative care nurses.**
International journal of palliative nursing 2010 May; 16(5): 233-40

Document 196
Asher, Joy Bickley
**Finding the right way to die.**
Document 197
McLennan, Stuart; Celi, Leo Anthony; Gillett, Grant; Penney, Judith; Foss, Mike
Nurses share their views on end-of-life issues.
Nursing New Zealand (Wellington, N.Z. : 1995) 2010 May ; 16(4): 12-4
Georgetown users check Georgetown Journal Finder for access to full text

Document 198
Kirk, Timothy W; Mahon, Margaret M;
National Hospice and Palliative Care Organization (NHPCO) position statement and commentary on the use of palliative sedation in imminently dying terminally ill patients.
Journal of pain and symptom management 2010 May ; 39(5): 914-23
Georgetown users check Georgetown Journal Finder for access to full text

Document 199
McBride, Deborah
Patients are more likely to choose comfort care after watching video on end-of-life options.
ONS connect 2010 May ; 25(5): 15
Georgetown users check Georgetown Journal Finder for access to full text

Document 200
Joyner, Nancy
Palliative care issues. Healthcare directives–DNR does not mean "do not treat".
The Prairie rose 2010 May-Jul; 79(2): 9-11
Georgetown users check Georgetown Journal Finder for access to full text

Document 201
McBride, Deborah
Patients are more likely to choose comfort care after watching video on end-of-life options.
ONS connect 2010 May ; 25(5): 15
Georgetown users check Georgetown Journal Finder for access to full text

Document 202
Berger, Jeffrey T.
Rethinking guidelines for the use of palliative sedation
Abstract: The use of continuous palliative sedation to unconsciousness rests on a consensus that leads quickly to controversy. Although there is consensus that it should be used only for terminally ill patients and even then reserved for cases in which severe symptoms persist despite efforts to find an alternative palliative treatment, authorities disagree about whether PSU is appropriate for existential suffering and about how close to death the
The patient should be before PSU is introduced. Some authorities stipulate that PSU should be withheld until the patient is within hours to days from death, while others specify no particular time frame. A patient sedated to unconsciousness generally dies from dehydration in two weeks or less unless—as in fact typically happens—they die first from the underlying disease. There is also a consensus within medicine that PSU is a medical treatment and is therefore not tantamount to active euthanasia. However, the consensus also holds that PSU should be subject to restrictions that do not otherwise apply to medical treatments. In short, PSU is both a medical treatment and subject to restrictions that are extraordinary in medicine. Medical authorities have not articulated a cogent medical and ethical rationale for this seeming contradiction. This article delves into this problem, along with some others associated with PSU, and offers revised guidelines for its use.

http://www.thehastingscenter.org/Publications/HCR/Archive.aspx (link may be outdated)
**Document 206**

Kettler, Dietrich; Nauck, Friedemann

**Palliative care and involvement of anaesthesiology: current discussions.**

Current opinion in anaesthesiology 2010 Apr; 23(2): 173-6

**Abstract:** PURPOSE OF REVIEW: To summarize various developments related to palliative care, especially related to ethical issues. To emphasize the involvement of anaesthesiology in palliative care. RECENT FINDINGS: Euthanasia has been legalized in Belgium, the Netherlands and Luxemburg (BENELUX countries). A group from Belgium has now proposed using euthanasia in patients in whom palliative care has been deemed 'futile'. This practice of so-called 'integral palliative care' is strongly rejected in a study from Germany. Palliative sedation is an ethically different approach with no intention to kill the patient. The European Association of Palliative Care has proposed a framework for individual guidelines for palliative sedation. The important role of anaesthesiology in palliative care teams is emphasized. SUMMARY: Palliative care is a powerful approach to patient care during terminal illness, emphasizing quality of life even if it may shorten the length of life. Traditionally, palliative care has been contrasted with active euthanasia, but a group from Belgium has challenged this concept recently, advocating the use of euthanasia in circumstances in which palliative care has become 'futile'. This new approach led to strong reactions by a group from Germany, stressing that killing on demand in palliative care should under no circumstances be justified. In contrast, palliative sedation is a common method in special cases to reduce intractable symptoms. A new framework for palliative sedation produced by the European Association of Palliative Care may encourage institutions to set up their own palliative sedation guidelines. Worldwide, anaesthesiologists have a significant role in palliative care due to their unique complex expertise mainly in pain therapy and including transient sedation of patients.

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**Document 207**

Bétrémieux, P; Gold, F; Parat, S; Famoux, C; Rajguru, M; Boithias, C; Mahieu-Caputo, D; Jouannic, J-M; Hubert, P; Simeoni, U

[Implementing palliative care for newborns in various care settings. Part 3 of "Palliative care in the neonatal period"] = La mise en oeuvre pratique des soins palliatifs dans les différents lieux de soins : 3(e) partie des réflexions et propositions autour des soins palliatifs en période néonatale.

Archives de pédiatrie : organe officiel de la Sociéte française de pédiatrie 2010 Apr; 17(4): 420-5

**Abstract:** Palliative care in newborns may take place in the delivery room and then continued either in maternity wards or in the neonatal unit. For babies developing a chronic condition, going home may be advantageous. The population concerned includes babies born with a severe intractable congenital malformation and certain extremely preterm newborn babies at the limits of viability. Care procedures as well as withholding and withdrawing treatments are reviewed.

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**Document 208**

Bétrémieux, P; Gold, F; Parat, S; Caeymaex, L; Danan, C; De Dreuzy, P; Vernier, D; Viallard, M-L; Kuhn, P


Archives de pédiatrie : organe officiel de la Sociéte française de pédiatrie 2010 Apr; 17(4): 409-12

**Abstract:** In France, the law dated 22 April 2005 required that all practitioners offer palliative care to patients as an alternative to unreasonable obstinacy. The practical development of palliative care during the neonatal period is not easy, even though obstetricians and neonatologists have always been aware of the ethical necessity of comfort in the dying newborn. The decision leading to palliative care begins with the recognition of patent or potential unreasonable obstinacy, followed by withdrawing treatment and technical support, and finally a palliative care plan is drawn up with the medical team and the parents.
Bétrémieux, P

[Palliative care in the neonatal period] = Réflexions et propositions autour des soins palliatifs en période néonatale : préambule.
Archives de pédiatrie : organe officiel de la Société française de pédiatrie 2010 Apr; 17(4): 407-8

Bétrémieux, P; Gold, F; Parat, S; Moriette, G; Huillery, M-L; Chabernaud, J-L; Storme, L; Narcy, P; Deruelle, P; Kracher, S

[Imagining a palliative care project for newborns. Part two of Palliative care in the neonatal period] = Construction d'un projet de soins palliatifs chez le nouveau-né : 2(e) partie des réflexions et propositions autour des soins palliatifs en période néonatale.
Archives de pédiatrie : organe officiel de la Société française de pédiatrie 2010 Apr; 17(4): 413-9

Schmid, Bettina; Allen, Rebecca S; Haley, Philip P; Decoster, Jamie

Family matters: dyadic agreement in end-of-life medical decision making.
The Gerontologist 2010 Apr; 50(2): 226-37

Abstract: PURPOSE: We examined race/ethnicity and cultural context within hypothetical end-of-life medical decision scenarios and its influence on patient-proxy agreement. DESIGN AND METHODS: Family dyads consisting of an older adult and 1 family member, typically an adult child, responded to questions regarding the older adult's preferences for cardiopulmonary resuscitation, artificial feeding and fluids, and palliative care in hypothetical illness scenarios. The responses of 34 Caucasian dyads and 30 African American dyads were compared to determine the extent to which family members could accurately predict the treatment preferences of their older relative. RESULTS: We found higher treatment preference agreement among African American dyads compared with Caucasian dyads when considering overall raw difference scores (i.e., overtreatment errors can compensate for undertreatment errors). Prior advance care planning moderated the effect such that lower levels of advance care planning predicted undertreatment errors among African American proxies and overtreatment errors among Caucasian proxies. In contrast, no racial/ethnic differences in treatment preference agreement were found within absolute difference scores (i.e., total error, regardless of the direction of error). IMPLICATIONS: This project is one of the first to examine the mediators and moderators of dyadic racial/cultural differences in treatment preference agreement for end-of-life care in hypothetical illness scenarios. Future studies should use mixed method approaches to explore underlying factors for racial differences in patient-proxy agreement as a basis for developing culturally sensitive interventions to reduce racial disparities in end-of-life care options.

Ettema, Eric J; Derksen, Louise D; van Leeuwen, Evert

Existential loneliness and end-of-life care: a systematic review.
Theoretical medicine and bioethics 2010 Apr; 31(2): 141-69

Abstract: Patients with a life-threatening illness can be confronted with various types of loneliness, one of which is existential loneliness (EL). Since the experience of EL is extremely disruptive, the issue of EL is relevant for the practice of end-of-life care. Still, the literature on EL has generated little discussion and empirical substantiation and
has never been systematically reviewed. In order to systematically review the literature, we (1) identified the existential loneliness literature; (2) established an organising framework for the review; (3) conducted a conceptual analysis of existential loneliness; and (4) discussed its relevance for end-of-life care. We found that the EL concept is profoundly unclear. Distinguishing between three dimensions of EL— as a condition, as an experience, and as a process of inner growth—leads to some conceptual clarification. Analysis of these dimensions on the basis of their respective key notions—everpresent, feeling, defence; death, awareness, difficult communication; and inner growth, giving meaning, authenticity—further clarifies the concept. Although none of the key notions are unambiguous, they may function as a starting point for the development of care strategies on EL at the end of life.

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Document 215

Hussainy, Safeera Yasmeen; Marriott, Jennifer L; Beattie, Jill; Nation, Roger L; Dooley, Michael J

**A palliative cancer care flexible education program for Australian community pharmacists.**

American journal of pharmaceutical education 2010 Mar 10; 74(2): 24

**Abstract:** To implement and evaluate a flexible palliative care education program for Australian community pharmacists.

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Document 216

Chambaere, Kenneth; Bilsen, Johan; Cohen, Joachim; Rietjens, Judith A; Onwuteaka-Philipsen, Bregje D; Mortier, Freddy; Deliens, Luc

**Continuous deep sedation until death in Belgium: a nationwide survey.**

Archives of Internal Medicine 2010 March 8; 170(5): 490-493

Georgetown users check [Georgetown Journal Finder](#) for access to full text

Document 217

Goldstein, Nathan; Carlson, Melissa; Livote, Elayne; Kutner, Jean S.

**Brief communication: Management of implantable cardioverter-defibrillators in hospice: A nationwide survey.**

Annals of Internal Medicine 2010 March 2; 152(5): 296-299

**Abstract:** BACKGROUND: Communication about the deactivation of implantable cardioverter-defibrillators (ICDs) in patients near the end of life is rare. OBJECTIVE: To determine whether hospices are admitting patients with ICDs, whether such patients are receiving shocks, and how hospices manage ICDs. DESIGN: Cross-sectional survey. SETTING: Randomly selected hospice facilities. PARTICIPANTS: 900 hospices, 414 of which responded fully. MEASUREMENTS: Frequency of admission of patients with ICDs, frequency with which patients received shocks, existence of ICD deactivation policies, and frequency of deactivation. RESULTS: 97% of hospices admitted patients with ICDs, and 58% reported that in the past year, a patient had been shocked. Only 10% of hospices had a policy that addressed deactivation. On average, 42% (95% CI, 37% to 48%) of patients with ICDs had the shocking function deactivated. LIMITATION: The study relied on the knowledge of hospice administrators. CONCLUSION: Hospices are admitting patients with ICDs, and patients are being shocked at the end of life. Ensuring that hospices have policies in place to address deactivation may improve the care for patients with these devices. The authors provide a sample deactivation policy. PRIMARY FUNDING SOURCE: National Institute of Aging and National Institute of Nursing Research.

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Document 218

Sulmasy, Daniel P.; Curlin, Farr; Brungardt, Gerard S.; Cavanaugh, Thomas

**Justifying different levels of palliative sedation.**

Annals of Internal Medicine 2010 March 2; 152(5): 332-333; author reply 333

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Document 219

Cellarius, Victor; Henry, Blair

**Justifying different levels of palliative sedation.**

Annals of Internal Medicine 2010 March 2; 152(5): 332; author reply 333
Document 220
McGinn, M
End of life care.
European journal of cancer care 2010 Mar; 19(2): 144
Abstract: This module presents background and encourages personal reflection and learning on end of life care terminology, concepts and ethics for all healthcare staff working with adult cancer patients. Consideration is given to resuscitation issues, communication skills competence and end of life care pathways such as Gold Standards Framework and Liverpool Care Pathway for the Dying.

Document 221
Cassell, Eric J; Rich, Ben A
Intractable end-of-life suffering and the ethics of palliative sedation.
Pain medicine (Malden, Mass.) 2010 Mar; 11(3): 435-8
Abstract: Palliative sedation (sedation to unconsciousness) as an option of last resort for intractable end-of-life distress has been the subject of ongoing discussion and debate as well as policy formulation. A particularly contentious issue has been whether some dying patients experience a form of intractable suffering not marked by physical symptoms that can reasonably be characterized as "existential" in nature and therefore not an acceptable indication for palliative sedation. Such is the position recently taken by the American Medical Association. In this essay we argue that such a stance reflects a fundamental misunderstanding of the nature of human suffering, particularly at the end of life, and may deprive some dying patients of an effective means of relieving their intractable terminal distress.

Document 222
Banja, John D
When moral arguments become intractable.
Pain medicine (Malden, Mass.) 2010 Mar; 11(3): 439; discussion 442

Document 223
Jansen, Lynn A
Pain medicine (Malden, Mass.) 2010 Mar; 11(3): 440-1; discussion 442

Document 224
Cassell, Eric J; Rich, Ben A
Intractable end-of-life suffering and the ethics of palliative sedation.
Pain medicine (Malden, Mass.) 2010 Mar; 11(3): 435-8
Abstract: Palliative sedation (sedation to unconsciousness) as an option of last resort for intractable end-of-life
distress has been the subject of ongoing discussion and debate as well as policy formulation. A particularly contentious issue has been whether some dying patients experience a form of intractable suffering not marked by physical symptoms that can reasonably be characterized as “existential” in nature and therefore not an acceptable indication for palliative sedation. Such is the position recently taken by the American Medical Association. In this essay we argue that such a stance reflects a fundamental misunderstanding of the nature of human suffering, particularly at the end of life, and may deprive some dying patients of an effective means of relieving their intractable terminal distress.
Hampton, Mary; Baydala, Angelina; Bourassa, Carrie; McKay-McNabb, Kim; Placsko, Cheryl; Goodwill, Ken; McKenna, Betty; McNabb, Pat; Boekelder, Roxanne

**Completing the circle: elders speak about end-of-life care with aboriginal families in Canada**
Journal of Palliative Care 2010 Spring; 26(1): 6-14

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**Document 237**

Duke, Sue; Bennett, Helen

**Review: a narrative review of the published ethical debates in palliative care research and an assessment of their adequacy to inform research governance.**
Palliative medicine 2010 Mar; 24(2): 111-26

**Abstract:** The quality of research, and the resulting quality of evidence available to guide palliative care, is dependent on the ethical decisions underpinning its design, conduct and report. Whilst much has been published debating the ethics of palliative care research, an assessment of the quality and synthesis of the central debates is not available. Such a review is timely to inform research governance. The methodology of this study is based on the principles of systematic reviews. Fifty-seven papers were reviewed following a thorough search, and were critically appraised for their literary quality, the knowledge on which they drew and the research standards they addressed. The debates identified address vulnerability, moral appropriateness, consent, gate-keeping and inclusion and research culture. The quality of debate and the sources of knowledge varied. The debate was rich in quality and knowledge with respect to the protection of the dignity, rights and safety of research participants, but less developed in relation to those of researchers and other staff. There is also little debate about the ethics of reporting of research and the ethics underpinning research leadership. A framework is offered that reconciles the ethical issues raised with potential methodological strategies identified from the review.

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**Document 238**

Mclarnon, Claire; Kulloo, Praneta; Mehanna, Hisham; Kelly, Charles; Paleri, Vinidh

**Quality-of-life considerations in treatment of unresectable, recurrent head and neck cancer.**
Expert review of anticancer therapy 2010 Mar; 10(3): 345-52

**Abstract:** Recurrent, unresectable head and neck squamous cancer is a complex problem. Evidence for the efficacy of treatment is scant in this area and given the large number of patient and tumor variables involved in the recurrent tumor, several factors play a role in deciding the choice of management. The results of treatment are very poor and associated with significant toxicity. Thus, the quality of life outcome following treatment should play a major role in the choice of treatment. Unfortunately, generation of quality-of-life data is hampered by several factors, not least of which are the ethical issues raised by end of life care. This article reviews the relevant literature, summarizes existing evidence and draws conclusions, identifies gaps in the knowledge and offers guidance for further research.

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**Document 239**

Payne, Kate

**Promises to keep: ethical obligations at the end of life.**
Tennessee Nurse 2010 Spring; 73(1): 4

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**Document 240**

Byock, Ira

**Dying with dignity.**
Keating, Nancy L.; Landrum, Mary Beth; Rogers, Selwyn O.; Baum, Susan K.; Virmig, Beth A.; Huskamp, Haiden A.; Earle, Craig C.; Kahn, Katherine L.

**Physician factors associated with discussions about end-of-life care.**
Cancer 2010 February 15; 116(4): 998-1006

Tucker, Kathryn L.

**The need for more accurate terminology in discussing end-of-life options.**
Archives of Internal Medicine 2010 February 8; 170(3): 307

Beauregard, Lou-Anne M

**Ethics in electrophysiology: a complaint from palliative care.**

Furman, Christian Davis; Doukas, David John; Reichel, William

**Unlocking the closed door: arguments for open access hospice.**
The American journal of hospice & palliative care 2010 Feb ; 27(1): 86-90

**Abstract:** The traditional view of standard hospice (SH) care is that once begun, the doorway toward curative and other forms of nonpalliative treatment is irrevocably locked. We will argue that such a traditional view needs to be reassessed in light of new arguments and data regarding access to these avenues of treatment. We will argue that patients should be supported in their transition from SH to open access hospice (OAH). Open access hospice should be available to all patients because of ethical arguments, patient satisfaction arguments, and costs of care arguments. More randomized controlled research trials need to be performed to study the impact of OAH versus SH. This research should focus on patient satisfaction, cost, and survival.

Gerkin, David G

**My dad's last gift: a redux.**
Tennessee medicine : journal of the Tennessee Medical Association 2010 Feb ; 103(2): 7-8
Document 246
Gerkin, David G

My dad's last gift: a redux.
Tennessee medicine: journal of the Tennessee Medical Association 2010 Feb; 103(2): 7-8

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Document 247
Williams, Brenda; Phelps, Greg; Misulis, Karl E; Cook, David M

End of life and the advance directive.
Tennessee medicine: journal of the Tennessee Medical Association 2010 Feb; 103(2): 19-26

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Document 248
Jansen, Lynn A.

Disambiguating clinical intentions: the ethics of palliative sedation.

Abstract: It is often claimed that the intentions of physicians are multiple, ambiguous, and uncertain—at least with respect to end-of-life care. This claim provides support for the conclusion that the principle of double effect is of little or no value as a guide to end-of-life pain management. This paper critically discusses this claim. It argues that proponents of the claim fail to distinguish two different senses of "intention," and that, as a result, they are led to exaggerate the extent to which clinical intentions in end-of-life contexts are ambiguous and uncertain. It argues further that physicians, like others who make life and death decisions, have a duty to get clear on what their intentions are. Finally, it argues that even if the principle of double effect should be rejected, clinical intentions remain ethically significant because they condition the meaning of extraordinary clinical interventions, such as that of palliative sedation.

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http://jmp.oxfordjournals.org/content/vol35/issue1/ (link may be outdated)

Document 249
Christopher, Stephanie A.

The relationship between nurses' religiosity and willingness to let patients control the conversation about end-of-life care.
Patient Education and Counseling 2010 February; 78(2): 250-255

Abstract: OBJECTIVE: The study attempts to examine the relationship between nurses' religious beliefs and how nurses communicate with patients. METHOD: An online census survey was administered to graduate students in the School of Nursing at a Midwestern university. The survey was designed to measure: relational control, as measured by the subscales of dominance and task orientation in Burgoon and Hale's scale of relational communication; clinician empathy, as measured by the Jefferson scale of clinician empathy; and intrinsic and extrinsic religiosity, whether religious views are held for deep personal reasons or social reasons, as measured by the Maltby and Lewis scale. Data were analyzed using multiple regressions and one-way ANOVAs. RESULTS: Intrinsic religiosity and empathy were both associated with the willingness to relinquish relational control in certain, specific contexts, such as end-of-life care. CONCLUSION: Nurses who scored higher on a scale of intrinsic religious beliefs were more willing to let patients take control of conversations about end-of-life care. PRACTICE IMPLICATIONS: A nurse's religious beliefs can enhance the clinical experience without the nurse trying to impose his or her beliefs on the patient, as the nurse works to make sure the patient's religious beliefs are upheld.
Document 250

Turner, Helen N.

**Parental preference or child well-being: an ethical dilemma.**

*Abstract:* An ethical dilemma that is not uncommon to encounter when caring for children occurs when parental preference does not appear to be in the child's best interest. Challenges facing the health care team are further amplified when the family's cultural background does not match that of the team. A case study will be used to illustrate the challenges of a pediatric palliative care ethical dilemma further complicated by cultural diversity. Review of the child's medical condition, patient/parent preferences, quality of life, and contextual features will be followed by an analysis and recommendations for resolution of this challenging situation.

Document 251

Kutner, Jean S.

**An 86-year-old woman with cardiac cachexia contemplating the end of her life: review of hospice care.**

*Abstract:* Mrs H is an 86-year-old woman with progressive congestive heart failure and multiple chronic conditions who is experiencing worsening function and quality of life despite maximum medical therapies. She seeks advice regarding control over the circumstances of the end of her life, be it by suicide or under hospice care. Typical of US populations older than 65 years with multiple chronic health conditions and functional decline who are facing the end of life, Mrs H's concerns are particularly about quality of life, not being a burden on loved ones, and maintaining control. As she demonstrates, psychological, existential, and social factors, particularly fear of being a burden, are more common reasons for desiring hastened death than those related directly to physical symptoms. Hospice, which provides a multidisciplinary approach to care at the end of life, can assist Mrs H and her family in making decisions that are consistent with her goals.

Document 252

Sheriff, Dhaustagir Sultan

'Take me home and allow me to die peacefully' - an ethical dilemma of grave concern.
The Libyan journal of medicine 2010 January 7; 5

Document 253

Barazzetti, Gaia; Borreani, Claudia; Miccinesi, Guido; Toscani, Franco

What "best practice" could be in Palliative Care: an analysis of statements on practice and ethics expressed by the main Health Organizations.
BMC palliative care 2010 January 7; 9: 1

*Abstract: ABSTRACT:*
Document 254

Díez Fernández, José Antonio

**Autonomía del Paciente y Deberes del Médico en el Proyecto de Ley Andaluza de "Muerte Digna" = Patients' Autonomy and doctors' duties according to the andalusian bill of "dignified dead"

Cuadernos de Bioética 2010 January-April; 21(71): 52-60

Georgetown users check [Georgetown Journal Finder](#) for access to full text

Document 255

Young, Judith S.; Stec, Mary Theresa

**Online resources for pediatric home care clinicians.**

Home Healthcare Nurse 2010 January; 28(1): 45-52

**Abstract:** Pediatric home care clinicians dealing with premature infants can encounter any number of unusual conditions related to their patient's prematurity. Finding reliable information on the condition can be difficult for a clinician who does not have immediate access to a health sciences library. There are, however, many useful, reliable websites that can be consulted with a laptop that has wireless access. This article reviews a variety of useful websites with a wealth of evidence-based information. The author also provides information on Health on the Net (HON), a nongovernmental, nonprofit organization that has established a code of conduct that websites must meet in order to display their seal.

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Document 256

Erichsen, Eva; Danielsson, Elisabeth Hadd; Friedrichsen, Maria

**A phenomenological study of nurses' understanding of honesty in palliative care.**

Nursing Ethics 2010 January; 17(1): 39-50

**Abstract:** Honesty is essential for the care of seriously ill and dying patients. The current study aimed to describe how nurses experience honesty in their work with patients receiving palliative care at home. The interviews in this phenomenological study were conducted with 16 nurses working with children and adults in palliative home-based care. Three categories emerged from analyses of the interviews: the meaning of honesty, the reason for being honest and, finally, moral conflict when dealing with honesty. The essence of these descriptions was that honesty is seen as a virtue, a good quality that a nurse should have. The nurses' ethical standpoint was shown in the moral character they show in their work and in their intention to do good. This study could help nurses to identify different ways of looking at honesty to promote more consciousness and openness in ethical discussions between colleagues and other staff members.

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Document 257

Jotkowitz, Alan; Zivotofsky, Ari Z.

"Love your neighbor like yourself": a Jewish ethical approach to the use of pain medication with potentially dangerous side effects.


**Abstract:** Palliation of pain is universally regarded as a cardinal aspect of end-of-life care. In the early days of the palliative care and hospice movement there was concern that aggressive pain control with opioids could potentially hasten the death of the patient primarily through respiratory depression. For many ethicists and theologians who were opposed to active euthanasia, this raised the difficult question of whether it is permissible to use these potentially harmful medications. Traditional Jewish decisors also addressed this question and their writings can shed light on their attitudes toward terminal care. The purpose of this article is to analyze the view of three highly respected authorities on the use of pain medications with potentially significant side effects in terminal patients. The Jewish position demonstrates how an ancient tradition struggles to develop an ethic consistent with modern...
sensibilities. Religious decisors scour the ancient sources to find precedents and then apply that wisdom to contemporary questions. Jewish medical ethics by its very nature is highly pluralistic because there is no central body that determines policy and a wide spectrum of opinions are usually found. However, regarding pain treatment there appears to be a broad consensus mandating its aggressive use even at the risk of significant side effects as long as the motivation is relief of suffering.

http://www.nber.org/papers/w15649.pdf (link may be outdated)
Document 264
Meier, Diane E.; Isaacs, Stephen L.; and Hughes, Robert G., eds.
PALLIATIVE CARE: TRANSFORMING THE CARE OF SERIOUS ILLNESS

Document 265
Bos, Gerard M J
[Solidarity with the healthcare sector is not boundless]. = Solidariteit in de zorg is niet onbegrens.
Nederlands tijdschrift voor geneeskunde 2010; 154(51-52): A2974
Abstract: Technological developments in healthcare help people to survive diseases that used to be fatal. Older people want to profit from new these opportunities as well, in order to live as long as possible. This puts tremendous pressure on solidarity. How long can we continue to increase expenditure on healthcare? Money spent on healthcare cannot be spent in other areas; there are limits to what we can afford.

Document 266
Kleeberg, Ulrich R
Promoting palliative care is prerequisite to future integrity of a comprehensive humane medicine.
Onkologie 2010; 33(11): 575-6

Document 267
Sampson, Elizabeth L
Palliative care for people with dementia.
British medical bulletin 2010; 96: 159-74
Abstract: The number of people with dementia will rise dramatically over the next 20 years. Currently, one in three people over the age of 65 will die with dementia. A PubMed search using MeSH headings for 'dementia' AND 'palliative care' and for specific areas, i.e. enteral feeding. National reports, UK guidelines and policies were also consulted. Advanced dementia is now being perceived as a 'terminal illness' with a similar symptom burden and prognosis to advanced cancer. People with dementia have poor access to good quality end-of-life care. Interventions such as antibiotics, fever management policies and enteral tube feeding remain in use despite little evidence that they improve quality of life or other outcomes. Research is required on the effectiveness of 'holistic' palliative care, outcome measures and the impact on carers and families.

Document 268
Mathiews, Ann Kimberlin
Death with dignity.
Creative nursing 2010; 16(4): 185-7
Abstract: The concept of death with dignity evolves over a nurse's career. A new nurse focuses on the patient as a person. As the nurse gains experience, she facilitates family grieving. As a seasoned professional, the nurse emphasizes the dignity that, through effective nursing, can be restored to dying. Preservation of dignity is found in
the way we honor death.

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**Document 269**

Iglesias, M L; Lafuente, A

[Care for the dying patient in emergency departments]. = Asistencia al paciente agónico que va a fallecer en urgencias.

Anales del sistema sanitario de Navarra 2010; 33 Suppl 1: 173-91

**Abstract:** The aim of this article is to provide professionals in the hospital emergency departments with sufficient tools to face, according to the organisation and possibilities of each hospital, the admission of patients in the final days of life. It is primordial to provide a professional, technical and human environment based on concepts, attitudes and skills that make it possible to deal with the demands of comfort and the emotional and psycho-social requirements generated by these situations.

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**Document 270**

Kurien, Matthew; McAlindon, Mark E.; Westaby, David; Sanders, David S.

Percutaneous endoscopic gastrostomy (PEG) feeding.

BMJ (Clinical research ed.) 2010; 340: c2414

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**Document 271**

Edmonds, Polly; Burman, Rachel

Enf of life care in the acute hospital setting [editorial]

British Medical Journal 2009 December 5; 339(7733): 1269-1270

http://www.bmj.com (link may be outdated)

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**Document 272**

Brody, Jane E

In hospice, care and comfort as life wanes

New York Times 2009 December 1; p. D7

http://www.nytimes.com (link may be outdated)

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**Document 273**

Staff of the Center for Ethics at Washington Hospital Center

Is this patient depressed or just sad?

Journal of Hospital Ethics 2009 Winter; 1(3): 18-19

Georgetown users check Georgetown Journal Finder for access to full text
Document 274
Kawagoe, Izumi; Ito, Mioko; Matsuura, Shinobu; Kawagoe, Koh
Home hospice care for the lung cancer patient living alone: a case report from Japan
Journal of Palliative Care 2009 Winter; 25(4): 289-293
Georgetown users check Georgetown Journal Finder for access to full text

Document 275
Cameron, Brenda L.; Salas, Anna Santos
Understanding the provision of palliative care in the context of primary health care: qualitative research findings from a pilot study in a community setting in Chile
Journal of Palliative Care 2009 Winter; 25(4): 275-283
Georgetown users check Georgetown Journal Finder for access to full text

Document 276
Mino, Jean-Christophe; Frattini, Marie-Odile
Chronic palliative care: specific practices for Alzheimer's disease sufferers
Journal of Palliative Care 2009 Winter; 25(4): 243-244
Georgetown users check Georgetown Journal Finder for access to full text

Document 277
Heyland, Daren K.; Frank, Christopher; Tranmer, Joan; Paul, Nancy; Pichora, Deborah; Jiang, Xuran; Day, Andrew G.
Satisfaction with end-of-life care: a longitudinal study of patients and their family caregivers in the last months of life
Journal of Palliative Care 2009 Winter; 25(4): 245-256
Georgetown users check Georgetown Journal Finder for access to full text

Document 278
Roy, David J.
Ambiguity in palliative care? [editorial]
Journal of Palliative Care 2009 Winter; 25(4): 243-244
Georgetown users check Georgetown Journal Finder for access to full text

Document 279
Van Wesemael, Yanna; Cohen, Joachim; Onwuteaka-Philipsen, Bregje D; Bilsen, Johan Distelmans, Wim; Deliens, Luc
Role and involvement of life end information forum physicians in euthanasia and other end-of-life care decisions in Flanders, Belgium.
Health services research 2009 Dec; 44(6): 2180-92
Abstract: OBJECTIVE: To describe role and involvement of Life End Information Forum (LEIF) physicians in end-of-life care decisions and euthanasia in Flanders. STUDY DESIGN: All 132 LEIF physicians in Belgium received a
questionnaire inquiring about their activities in the past year, and their end-of-life care training and experience.
PRINCIPAL FINDINGS: Response rate was 75 percent. Most respondents followed substantive training in end-of-life care. In 1 year, LEIF physicians were contacted 612 times for consultations in end-of-life decisions, of which 355 concerned euthanasia requests eventually resulting in 221 euthanasia cases. LEIF physicians also gave information about various end-of-life issues (including palliative care) to patients and colleagues. CONCLUSIONS: LEIF physicians provide a forum for information and advice for physicians and patients. A similar health service providing support to physicians for all end-of-life decisions could also be beneficial for countries without a euthanasia law.

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Document 280
Arao, Yuki; Sasabe, Mayako; Yamada, Yukari; Motoyama, Yuki; Morita, Katsuko; Kawazoe, Masahiro; Ono, Yoshiharu
[A consideration of the support for terminal care at the private skilled nursing home]
Gan to kagaku ryoho. Cancer & chemotherapy 2009 Dec; 36 Suppl 1(): 42-4
Abstract: The increase in the number of residents in elderly care facilities has developed into a growing demand for home-based terminal care rather than treatments at medical institutions. Like many others, the Active Life Toyonaka (private skilled nursing home) has received more requests from its residents for adequate terminal care. It is unfortunate, however, that quite a few residents are obliged to be hospitalized for medical reasons that result in death. The purpose of our study is to determine what a terminal care should be like in a private skilled nursing home. The study has been conducted with the focus on the successful case of a 90-year-old male resident diagnosed as having prostate cancer with bone metastasis. Our study has concluded that the crucial factors for a better terminal care should go as follows: (1) Having good coordination with medical institutions, (2) Reporting every change in residents' condition and administering an immediate treatment for alleviating pains of the residents, (3) Providing the residents with comfortable life of less restraint on activities in home-based care, (4) Sharing the same information among the staff of all divisions who is in charge of residents (doctors, nurses, caregivers, etc.) and (5) Establishing relationships of mutual trust with residents and their families. Nurses, especially, need to play important roles as coordinators among all the personnel concerned.

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Document 281
Paton, Alex
Letting go [commentary]
British Medical Journal 2009 November 28; 339(7732): 1259
http://www.bmj.com (link may be outdated)

Document 282
Dyer, Clare
Parents go to court over whether to allow baby son to die [news]
British Medical Journal 2009 November 7; 339(7729): 1048
http://www.bmj.com (link may be outdated)

Document 283
Barilan, Y Michael
Nozick's experience machine and palliative care: revisiting hedonism.

Abstract: In refutation of hedonism, Nozick offered a hypothetical thought experiment, known as the Experience Machine. This paper maintains that end-of-life-suffering of the kind that is resistant to state-of-the-art palliation provides a conceptually equal experiment which validates Nozick's observations and conclusions. The observation that very many terminal patients who suffer terribly do no wish for euthanasia or terminal sedation is incompatible with motivational hedonism. Although irreversible vegetative state and death are equivalently pain-free, very many people loath the former even at the price of the latter. This attitude cannot be accounted for by hedonism. Following these observations, the goals of palliative care are sketched along four circles. The first is mere removal or mitigation of noxious symptoms and suffering. The second targets sufferings that stymie patients' life-plans and do not allow them to be happy, the third targets sufferings that interfere with their pursuance of other goods (palliation as a primary good). The fourth is the control of sufferings that do not allow the person to benefit from any human good whatsoever ("total pain" or critical suffering). Only in the fourth circle are people hedonists.

Georgetown users check Georgetown Journal Finder for access to full text
Inghelbrecht, E; Bilsen, J; Mortier, F; Deliens, L
Nurses' attitudes towards end-of-life decisions in medical practice: a nationwide study in Flanders, Belgium.
Palliative medicine 2009 Oct ; 23(7): 649-58

Abstract: We investigated on a nationwide level the attitudes of nurses towards end-of-life decisions (ELDs) that may hasten death and towards their role in those decisions. We took a representative random sample of 6000 nurses in Flanders, Belgium. Response rate was 62.5%. Most nurses agreed with the practice of withholding/withdrawing potentially life-prolonging treatments (93%), with decisions to alleviate symptoms with possible life-shortening side effects (96%) and with the practice of euthanasia (92%). Their support for the different decisions existed regardless of whether they had cared for terminally ill patients or not. Most nurses also thought that they have an important role to play especially in the ELD-making process. Nurses’ views on their proper role in the administration of drugs in euthanasia and continuous deep sedation showed a large dispersal. Overall, nurses' work setting determines their opinions on nurses' role in ELDs. In conclusion, nurses accept a wide variety of ELDs being practiced with terminally ill patients.

Cherny, Nathan I; Radbruch, Lukas; European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care.
Palliative medicine 2009 Oct ; 23(7): 581-93

Abstract: The European Association for Palliative Care (EAPC) considers sedation to be an important and necessary therapy in the care of selected palliative care patients with otherwise refractory distress. Prudent application of this approach requires due caution and good clinical practice. Inattention to potential risks and problematic practices can lead to harmful and unethical practice which may undermine the credibility and reputation of responsible clinicians and institutions as well as the discipline of palliative medicine more generally. Procedural guidelines are helpful to educate medical providers, set standards for best practice, promote optimal care and convey the important message to staff, patients and families that palliative sedation is an accepted, ethical practice when used in appropriate situations. EAPC aims to facilitate the development of such guidelines by presenting a 10-point framework that is based on the pre-existing guidelines and literature and extensive peer review.

ven den Block, Lieve; Deschepper, Reginald; Bilsen, Johan; Bossuyt, Nathalie; Van Casteren, Viviane; Deliens, Luc
End of life decisions [letter]
British Medical Journal 2009 September 19; 339(7722): 648-649

Seccareccia, Dori; Brown, Judith Belle
Impact of spirituality on palliative care physicians: personally and professionally.
Journal of palliative medicine 2009 Sep; 12(9): 805-9
Abstract: Modern palliative care defines four key domains fundamental to a patients' holistic care: physical, emotional, social, and spiritual. Regardless of the symptom being addressed, all four domains of care may need to be addressed to reduce suffering and encourage healing. Yet, despite the spiritual domain consistently being asserted as an integral part of palliative care, more is written on how to provide the physical, emotional, and social aspects of care than on how to provide spiritual care.

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Document 292
Payne, Sheila; Froggatt, Katherine; O'Shea, Eamon; Murphy, Kathy; Larkin, Philip; Casey, Dympna; Léime, Aine Ni
*Improving palliative and end-of-life care for older people in Ireland: a new model and framework for institutional care*
Journal of Palliative Care 2009 Autumn; 25(3): 218-226

Georgetown users check [Georgetown Journal Finder](#) for access to full text.

Document 293
Davis, George F.
*The diagnosis of dying.*
Journal of Clinical Ethics 2009 Fall; 20(3): 262-263

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Document 294
Chiu, Tai-Yuan; Hu, Wen-Yu; Huang, Hsien-Liang; Yao, Chien-An; Chen, Ching-Yu
*Prevailing ethical dilemmas in terminal care for patients with cancer in Taiwan.*
Journal of Clinical Oncology 2009 August 20; 27(24): 3964-3968

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Document 295
Hartocollis, Anemona
*At the end, offering not a cure but comfort*

[http://www.nytimes.com](http://www.nytimes.com) (link may be outdated)

Document 296
Brody, Jane
*One piece of health reform: avoiding "bad" deaths*
New York Times 2009 August 18; p. D7

[http://www.nytimes.com](http://www.nytimes.com) (link may be outdated)
Byock, Ira
Euthanasia and other end of life decisions and care provided in final three months of life: nationwide retrospective study in Belgium.
British Medical Journal 2009 August 15; 339(7717): 390

Byock, Ira
End of life decisions and quality of care before death. [editorial]
British Medical Journal 2009 August 15; 339(7717): 357-358

Lane, Charles
Undue influence: the House bill skews end-of-life
Washington Post 2009 August 8; p. A13

Freeman, Shanna L; Berger, Ann M
Nebraska veterans' preferences for end-of-life care.
Clinical journal of oncology nursing 2009 Aug; 13(4): 399-403

Gross, Jane
With faith and friends, convent offers model for end of life
New York Times 2009 July 9; p. A1, A18
Document 302
Mohanti, Bidhu K
**Ethics in palliative care.**
Georgetown users check [Georgetown Journal Finder](http://www.georgetownjournalfinder.com) for access to full text

Document 303
Cherny, N.
**The use of sedation to relieve cancer patients' suffering at the end of life: addressing critical issues.**
Annals of Oncology 2009 July; 20(7): 1153-1155
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Document 304
Iglehart, John K.
**A new era of for-profit hospice care -- the Medicare benefit.**
Georgetown users check [Georgetown Journal Finder](http://www.georgetownjournalfinder.com) for access to full text

Document 305
Wilcock, Andrew; Crosby, Vincent; Chambers, John C.
**Hospices and CPR guidelines [letters]**
BMJ: British Medical Journal 2009 June 13; 338(7708): 1405-1406
Georgetown users check [Georgetown Journal Finder](http://www.georgetownjournalfinder.com) for access to full text

Document 306
Shemesh, Avraham Ofir
"The powerful drug:" opium and its derivatives in medieval and modern medicine in the light of Jewish literature
ASSIA: Jewish Medical Ethics 2009 June; 7(1): 61-70
Georgetown users check [Georgetown Journal Finder](http://www.georgetownjournalfinder.com) for access to full text

Document 307
Breitbart, William
**The spiritual domain of palliative care: who should be "spiritual care professionals"?**
Palliative and Supportive Care 2009 June; 7(2): 139-141
Georgetown users check [Georgetown Journal Finder](http://www.georgetownjournalfinder.com) for access to full text
Document 308
Simon, Alfred
Understanding the key areas of clinical decision making at the end of life.
Georgetown users check Georgetown Journal Finder for access to full text

Document 309
Materstvedt, Lars Johan; Bosshard, Georg
Deep and continuous palliative sedation (terminal sedation): clinical-ethical and philosophical aspects.
Lancet Oncology 2009 June; 10(6): 622-627
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Document 310
Huskamp, Haiden A.; Keating, Nancy L.; Malin, Jennifer L.; Zaslavsky, Alan M.; Weeks, Jane C.; Earle, Craig C.; Teno, Joan M.; Virnig, Beth A.; Kahn, Katherine L.; He, Yulei; Ayanian, John Z.
Discussions with physicians about hospice among patients with metastatic lung cancer.
Archives of Internal Medicine 2009 May 25; 169(10): 954-962
http://archinte.ama-assn.org (link may be outdated)

Document 311
Watson, Max; McPherson, Alan; Murray, Scott A.; Regnard, Claud; Randall, Fiona
Should hospices be exempt form following national CPR guidelines? [debate]
BMJ: British Medical Journal 2009 May 16; 338(7704): 1176-1177
http://www.bmj.com (link may be outdated)

Document 312
Dyer, Clare
More people should be given the chance to die at home, MPs say [news]
BMJ: British Medical Journal 2009 May 16; 338(7704): 1163
http://www.bmj.com (link may be outdated)

Document 313
Hauser, Joshua M.
Lost in transition: the ethics of the palliative care handoff.
Journal of Pain and Symptom Management 2009 May; 37(5): 930-933
**Document 314**

Savory, Eric A; Marco, Catherine A

**End-of-life issues in the acute and critically ill patient.**

Scandinavian journal of trauma, resuscitation and emergency medicine 2009 April 22; 17: 21

**Abstract:** The challenges of end-of-life care require emergency physicians to utilize a multifaceted and dynamic skill set. Such skills include medical therapies to relieve pain and other symptoms near the end-of-life. Physicians must also demonstrate aptitude in comfort care, communication, cultural competency, and ethical principles. It is imperative that emergency physicians demonstrate a fundamental understanding of end-of-life issues in order to employ the versatile, multidisciplinary approach required to provide the highest quality end-of-life care for patients and their families.

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**Document 315**

Wright, B; Aldridge, J; Wurr, K; Sloper, T; Tomlinson, H; Miller, M

**Clinical dilemmas in children with life-limiting illnesses: decision making and the law.**

Palliative medicine 2009 Apr; 23(3): 238-47

**Abstract:** Decision making about interventions for children and young people with life-limiting illnesses is fraught with difficulties but faced regularly by staff in children's hospices and paediatric wards. The perspectives of the child, various family members and professionals may all be different. The process of discussion and negotiation and the mechanism by which a decision is arrived at is complex. Various laws have recently changed in the UK that have an impact on this process. This article discusses several clinical scenarios to better understand these decisions and the effects of changes in the law. It also discusses how multidisciplinary teams in children's hospices (and other supportive clinical systems) can best support young people and families with and without recourse to the law.

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**Document 316**

Seale, C

**End-of-life decisions in the UK involving medical practitioners.**

Palliative medicine 2009 Apr; 23(3): 198-204

**Abstract:** This study estimates the frequency of different medical end-of-life decisions (ELDs) made in the United Kingdom (UK) in 2007-2008, comparing these with 2004. Postal survey was carried out with 8857 medical practitioners, of whom 3733 (42%) practitioners replied, with 2869 having attended a person who died in the previous year. The proportion of UK deaths involving (1) voluntary euthanasia (0.21%; CI: 0-0.52), (2) physician-assisted suicide (0.00%) and (3) ending of life without an explicit request from the patient (0.30%; CI: 0-0.60) is low. Better questions about ELDs showed both non-treatment decisions (21.8%; CI: 19.0-24.5) and double effect measures (17.1%; CI: 14.6-19.6) to be much less common than suggested in earlier estimates, rarely involving intent to end life or being judged to have shortened life by more than a day. Continuous deep sedation (16.5%; CI: 14.3-18.7) is relatively common in UK medical practice, particularly in hospitals, home care settings and with younger patients. Further findings about the distribution of ELDs across subgroups are also reported. Survey research in this area requires careful control over question wording if valid estimates and comparisons of the prevalence of ELDs are to be made. The high rate of sedation compared with other countries may be a cause for concern.

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**Document 317**

Viola, Deborah; Leven, David C; LePere, Jean C

**Abstract:** CONTEXT: Patients frequently rely on religious faith to cope with cancer, but little is known about the associations between religious coping and the use of intensive life-prolonging care at the end of life. OBJECTIVE: To determine the way religious coping relates to the use of intensive life-prolonging end-of-life care among patients with advanced cancer. DESIGN, SETTING, AND PARTICIPANTS: A US multisite, prospective, longitudinal cohort of 345 patients with advanced cancer, who were enrolled between January 1, 2003, and August 31, 2007. The Brief RCOPE assessed positive religious coping. Baseline interviews assessed psychosocial and religious/spiritual measures, advance care planning, and end-of-life treatment preferences. Patients were followed up until death, a median of 122 days after baseline assessment. MAIN OUTCOME MEASURES: Intensive life-prolonging care, defined as receipt of mechanical ventilation or resuscitation in the last week of life. Analyses were adjusted for demographic factors significantly associated with positive religious coping and any end-of-life outcome at P < .05 (i.e., age and race/ethnicity). The main outcome was further adjusted for potential psychosocial confounders (e.g., other coping styles, terminal illness acknowledgment, spiritual support, preference for heroics, and advance care planning). RESULTS: A high level of positive religious coping at baseline was significantly associated with receipt of mechanical ventilation compared with patients with a low level (11.3% vs 3.6%; adjusted odds ratio [AOR], 2.81 [95% confidence interval {CI}, 1.03-7.69]; P = .04) and intensive life-prolonging care during the last week of life (13.6% vs 4.2%; AOR, 2.90 [95% CI, 1.14-7.35]; P = .03) after adjusting for age and race. In the model that further adjusted for other coping styles, terminal illness acknowledgment, support of spiritual needs, preference for heroics, and advance care planning (do-not-resuscitate order, living will, and health care proxy/durable power of attorney), positive religious coping remained a significant predictor of receiving intensive life-prolonging care near death (AOR, 2.90 [95% CI, 1.07-7.89]; P = .04). CONCLUSIONS: Positive religious coping in patients with advanced cancer is associated with receipt of intensive life-prolonging medical care near death. Further research is needed to determine the mechanisms for this association.

Self-care of physicians caring for patients at the end of life: "Being connected... a key to my survival".

**Abstract:** Physicians providing end-of-life care are subject to a variety of stresses that may lead to burnout and compassion fatigue at both individual and team levels. Through the story of an oncologist, we discuss the prodromal symptoms and signs leading to burnout and compassion fatigue and present the evidence for prevention. We define and discuss factors that contribute to burnout and compassion fatigue and consider factors that may mitigate burnout. We explore the practice of empathy and discuss an approach for physicians to maximize wellness through self-awareness in the setting of caring for patients with end-stage illness. Finally, we discuss some practical applications of self-care in the workplace.
**Document 320**
Bågenholm, Eva Nilsson

*The arrest raises many questions = Häkningen väcker många frågor.*

Läkartidningen 2009 March 11-17; 106(11): 731

Georgetown users check [Georgetown Journal Finder](http://library.georgetown.edu) for access to full text

**Document 321**

Smith, Alexander K; Sudore, Rebecca L.; Pérez-Stable, Eliseo J.

*Palliative care for Latino patients and their families: whenever we prayed, she wept.*

JAMA: The Journal of the American Medical Association 2009 March 11; 301(10): 1047-1057

Georgetown users check [Georgetown Journal Finder](http://library.georgetown.edu) for access to full text

**Document 322**

Hasselaar, Jeroen G.J.; Verhagen, Stans C.A.H.H.V.M.; Wolff, André P.; Engels, Yvonne; Cru, Ben J.P.; Vissers, Kris C.P.

*Changed patterns in Dutch palliative sedation practices after the introduction of a national guideline.*

Archives of Internal Medicine 2009 March 9; 169(5): 430-437

**Abstract:** BACKGROUND: Continuous sedation, contrary to euthanasia, has been increasingly accepted among medical professionals worldwide. In the Netherlands, a national guideline for continuous palliative sedation has been developed to contribute to the quality of palliative sedation practice. The present follow-up study investigated whether the practice of continuous sedation has changed after the introduction of this guideline. METHODS: This study compared the practice of continuous sedation before and after the introduction of the guideline on December 7, 2005. A baseline measurement was performed between February 1, 2003, and May 1, 2005, with an enrollment of 492 physicians (medical specialists, general practitioners, and nursing home physicians). From January 1 to June 30, 2007, after the introduction of a national guideline for palliative sedation, a follow-up study was performed with the respondents of the baseline study. Physicians were asked to report on their last case of deep and continuous sedation in the past 12 months. RESULTS: This study reports the results of the follow-up study and compares them to the results of the baseline study. The response rate was 69.3% (n = 341). Of these physicians, 160 reported a last case of continuous sedation in both the baseline and the follow-up studies. Physicians reported a significant increase in patient involvement in decision making, from 72.3% to 82.2%. Pain remained the most often reported reason to start sedation, whereas exhaustion as a reason for sedation increased. The use of benzodiazepines increased from 69.9% to 90.4%. In the first and second measurements, symptom-directed treatment during sedation was applied in 56% to 58% of the cases. In the second period, there was more often an explicit decision to not give artificial hydration during sedation (78.8% vs 56.3%). Of the physicians, 34.2% were convinced that sedation shortened the life of the patient because of dehydration. CONCLUSIONS: After the introduction of the guideline, physicians reported that changes in palliative sedation practice conform to the recommendations of this guideline. For example, benzodiazepines were used for sedation more frequently than before and patient involvement in the decision-making process improved. Possible effects of dehydration and the large variation in symptom-directed treatment during sedation deserve careful attention.

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**Document 323**

Back, Anthony L.; Young, Jessica P.; McCown, Ellen; Engelberg, Ruth A.; Vig, Elizabeth K.; Reinke, Lynn F.; Wenrich, Marjorie D.; McGrath, Barbara B.; Curtis, J. Randall

*Abandonment at the end of life from patient, caregiver, nurse, and physician perspectives: loss of continuity and lack of closure.*

http://archinte.ama-assn.org (link may be outdated)
BACKGROUND: Surveys and anecdotes suggest that patients and family members sometimes feel abandoned by their physicians at the transition to end-of-life care. To our knowledge, no prior studies describe abandonment prospectively. METHODS: We conducted a longitudinal, qualitative study of patients, family caregivers, physicians, and nurses using a community-based sample. Using a purposive strategy, we recruited 31 physicians who identified 55 patients with incurable cancer or advanced chronic obstructive pulmonary disease, 36 family caregivers, and 25 nurses. Eligible patients met the prognostic criterion that their physician "would not be surprised" if death occurred within a year. Qualitative, semistructured interviews were performed at enrollment, 4 to 6 months, and 12 months and were audiotaped, transcribed, and coded by an interdisciplinary team. When asked to talk about hope and prognostic information, participants spontaneously raised concerns about abandonment, and we incorporated this topic into our interview guide. RESULTS: Two themes were identified: before death, abandonment worries related to loss of continuity between patient and physician; at the time of death or after, feelings of abandonment resulted from lack of closure for patients and families. Physicians reported lack of closure but did not discuss this as abandonment. CONCLUSIONS: The professional value of nonabandonment at the end of life consists of 2 different elements: (1) providing continuity, of both expertise and the patient-physician relationship; and (2) facilitating closure of an important therapeutic relationship. Framing this professional value as continuity and closure could promote the development of interventions to improve this aspect of end-of-life care.
EthxWeb Search Results

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Journal of Palliative Care 2009 Spring; 25(1): 40-50
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Rosengarten, Ora S.; Lamed, Yonat; Zisling, Timna; Feigin, Ayelet; Jacobs, Jeremy M.
Palliative sedation at home
Journal of Palliative Care 2009 Spring; 25(1): 5-11
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Chochinov, Harvey Max
The culture of research in palliative care: you probably think this song is about you.
Georgetown users check Georgetown Journal Finder for access to full text

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Avery, Jonathan
A story worth telling.
Georgetown users check Georgetown Journal Finder for access to full text

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Sanft, Tara; Hauser, Joshua; Rosielle, Drew; Weissman, David; Elsayem, Ahmed; Zhukovsky, Donna S.; Coyle, Nessa
Physical pain and emotional suffering: the case for palliative sedation.
Georgetown users check Georgetown Journal Finder for access to full text
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Gillick, Muriel R.

Potential burdens of low-tech interventions near the end of life.


Georgetown users check [Georgetown Journal Finder](#) for access to full text

**Document 332**

Garrard, Eve; Wrigley, Anthony

Hope and terminal illness: false hope versus absolute hope

Clinical Ethics 2009 March; 4(1): 38-43

Abstract: Sustaining hope in patients is an important element of health care, allowing improvement in patient welfare and quality of life. However in the palliative care context, with patients who are terminally ill, it might seem that in order to maintain hope the palliative care practitioner would sometimes have to deceive the patient about the full nature or prospects of their condition by providing a ‘false hope’. This possibility creates an ethical tension in palliative practice, where the beneficent desire to improve patient welfare through sustaining hope appears to be in conflict with an autonomy-based requirement not to deceive patients about their condition. In order to resolve this ethical tension, we provide an analysis of the concept of hope and argue that there is at least one conception - the ‘absolute’ conception of hope - which when properly understood allows practitioners to foster hope in terminally-ill patients while avoiding any need to deceive them about their condition. Practitioners therefore do not need to shy away from using the language of hope in the palliative setting, as on this understanding of hope it can be used in a way that both promotes patient welfare and respects patient autonomy.

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**Document 333**

Diamond, Eugene F.

Congenital anomalies

National Catholic Bioethics Quarterly 2009 Spring; 9(1): 35-45

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Johnson, Mark R.D.

End of life care in ethnic minorities [editorial]

BMJ: British Medical Journal 2009 February 28; 338(7693): 489-490

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Materstvedt, Lars Johan; Forde, Reidun

Retningslinjene for lindrende sederings bor revideres = Guidelines for palliative sedation should be revised

Tidsskrift for den Norske Lægeforening 2009 February 26; 129(5): 426-428
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JAMA: The Journal of the American Medical Association 2009 February 25; 301(8): 807-808

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JAMA: The Journal of the American Medical Association 2009 February 11; 301(6): 651-659

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Life saving treatment for a "palliative care" patient
BMJ: British Medical Journal 2009 February 7; 338(7690): 355-356

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Potera, Carol
End-of-life conversations benefit patients and caregivers [news]
American Journal of Nursing 2009 February; 109(2): 21

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American Journal of Nursing 2009 February; 109(2): 11
Moral reflections on neonatal intensive care.
Pediatrics 2009 February; 123(2): 595-597

Withdraw life support on the basis of substituted judgment

Write a do-not-resuscitate order and transfer the patient to a skilled nursing facility

Continue aggressive care and pursue an ethics consultation with the patient's surrogate

Clinical decisions. Care of an unresponsive patient with a poor prognosis.
Becker, Robert

**The real test of society is how it deals with dying people.**
Nursing Times 2009 January 27-February 2; 105(3): 11

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A conversation with: Robert Martensen; Most Americans die in hospitals or nursing homes, and neither is configured to take care of dying patients

Bowron, Craig

The dying of the light: The drawn-out indignities of the American way of death
Washington Post 2009 January 11; p. B1, B4

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NICE lifts cost limit on drugs to improve access to end of life treatments [news]
BMJ: British Medical Journal 2009 January 10; 338(7686): 67

Berlinger, Nancy

Of policy and pancakes
**Document 358**
Werth, James L. and Blevins, Dean, eds.
**DECISION MAKING NEAR THE END OF LIFE: ISSUES, DEVELOPMENTS, AND FUTURE DIRECTIONS**

**Document 359**
Chochinov, Harvey Max and Breitbart, William, eds.
**HANDBOOK OF PSYCHIATRY IN PALLIATIVE MEDICINE**
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Kort, Susanne Joëlle de
**AIMS AND REASONS: ETHICAL QUESTIONS ABOUT PALLIATIVE SYSTEMIC ANTICANCER THERAPY**
Amsterdam: s.l., 2009. 144 p.
Call number: RC271 .P33 K67 2009

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Swinton, John and Payne, Richard, eds.
**LIVING WELL AND DYING FAITHFULLY: CHRISTIAN PRACTICES FOR END-OF-LIFE CARE**
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Dolan, Susan and Vizzard, Audrey
**THE END OF LIFE ADVISOR: PERSONAL, LEGAL, AND MEDICAL CONSIDERATIONS FOR A PEACEFUL, DIGNIFIED DEATH**
Call number: R726.8 .D648 2009

**Document 363**
Pahor, Majda; Rasmussen, Birgit H
*How does culture show? A case study of an international and interprofessional course in palliative care.*
Journal of interprofessional care 2009; 23(5): 474-85

**Abstract:** Research shows slow improvement of the care of dying persons and their significant others. One of the reasons for that is the lack of palliative care education as an integral part of health professionals’ undergraduate education. The paper discusses an attempt to develop innovative forms of palliative care education: an international, interprofessional and IT-supported undergraduate course for Swedish and Slovenian students of nursing, medicine, occupational therapy, physiotherapy, psychology and social work, which has been developed jointly by the two authors. One of the aims of the course has been to address differences in professional and national cultures relevant to quality in palliative care. The development and pilot implementation phases of the course were analysed qualitatively, using evaluation materials from students and teachers and from an external evaluation study. The results show that the interprofessional approach in the course enabled students to get to know other professions, as well as enabling them to work together as a team and resolve conflicts. Cultural differences between Sweden and Slovenia were not very pronounced, yet they came to the fore regarding teamwork and relationships between
professions, as well as in respect of the "right thing" to do in relation to patient' problems.

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New perspectives on the end of life
Journal of Bioethical Inquiry 2009; 6(3): 269-270
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Call number: R724 .O7445 2009

*  Document 366
Dekkers, Wim
On the notion of home and the goals of palliative care.
Theoretical Medicine and Bioethics 2009; 30(5): 335-349
Abstract: The notion of home is well known from our everyday experience, and plays a crucial role in all kinds of narratives about human life, but is hardly ever systematically dealt with in the philosophy of medicine and health care. This paper is based upon the intuitively positive connotation of the term "home." By metaphorically describing the goal of palliative care as "the patient's coming home," it wants to contribute to a medical humanities approach of medicine. It is argued that this metaphor can enrich our understanding of the goals of palliative care and its proper objectives. Four interpretations of "home" and "coming home" are explored: (1) one's own house or homelike environment, (2) one's own body, (3) the psychosocial environment, and (4) the spiritual dimension, in particular, the origin of human existence. Thinking in terms of coming home implies a normative point of view. It represents central human values and refers not only to the medical-technical and care aspects of health care, but also to the moral context.
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Payne, Richard
Hope in the face of terminal illness
Call number: R726 .L556 2009

*  Document 368
Puchalski, Christina M.
Compassion: a critical component of caring and healing
Call number: R726 .L556 2009
Evans, Abigail Rian

**Healing in the midst of dying: a collaborative approach to end-of-life care**


Call number: [R726 .L556 2009]

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Pellegrino, Edmund D.; Sulmasy, Daniel P.

**Ethical issues in palliative care**


Call number: [R726.8 .P778 2009]

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Bonin-Scaon, Sylvie; Sastre, María Teresa Muñoz; Chasseigne, Gérard; Sorum, Paul C.; Mullet, Etienne

**End-of-life preferences: a theory-driven inventory.**


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Wiegand, Debra

**Palliative care**


Call number: [QH332 .P46 2009]

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Corcoran, Amy M.; Kapo, Jennifer M.

**Hospice: past, future, and ethical considerations**


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**The ethics of perinatal palliative care**


Call number: [QH332 .P46 2009]

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Cohn, Felicia


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De Gendt, Cindy; Bilsen, Johan; Mortier, Freddy; Vander Stichele, Robert; Deliens, Luc

*End-of-life decision-making and terminal sedation among very old patients.*


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*Palliative care: the relief you need when you're experiencing the symptoms of serious illness*


**Document 378**

United Kingdom. General Medical Council [GMC]

*End of life treatment and care: Good practice in decision-making. A draft for consultation*


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Groenhout, Ruth E.

*When life ends*


Call number: R725.56 .G76 2009

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Vargas, Theresa

*A resting place at last*

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Jusi?, Anica

Key ethic discussions in hospice/palliative care = Kljucne eticke rasprave u hospicijskoj/palijativnoj skrbi.
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Chochinov, Harvey Max; Hassard, Thomas; McClement, Susan; Hack, Thomas; Kristjanson, Linda J; Harlos, Mike; Sinclair, Shane; Murray, Alison

The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care.
Journal of Pain and Symptom Management 2008 December; 36(6): 559-571
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[Palliative care: interfaces, conflicts and necessities] = Cuidados paliativos: interfaces, conflitos e necessidades.
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Canadian Family Physician Médecin de Famille Canadien 2008 December; 54(12): 1651
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Palliative care as a human right.
Palliative and Supportive Care 2008 December; 6(4): 323-325
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Research priorities in pediatric palliative care: a Delphi study
Journal of Palliative Care 2008 Winter; 24(4): 229-239
Georgetown users check [Georgetown Journal Finder] for access to full text

Comparative legal aspects of pain management
Abstract: Administering pain medication to terminal patients can cause legal problems when it has a life-shortening effect, because according to some authors it equates with manslaughter. The legal basis of the acceptance of pain alleviation with life-shortening effect can be found on the grounds of necessity. In different countries physicians have been prosecuted because of their pain management, which to the public prosecutor was in fact a sort of euthanasia. On the other hand, it is not unknown that physicians administer opioids to mask euthanasia. Pain management needs some rules, which can reassure the physician who alleviates pain. The physician who alleviates pain with life-shortening effect will have to act with due care to avoid a liability risk. This implies at least an informed consent, to observe the proportionality rule, and to keep a medical record.
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Vansweevelt, T.
Comparative legal aspects of pain management
Abstract: Administering pain medication to terminal patients can cause legal problems when it has a life-shortening effect, because according to some authors it equates with manslaughter. The legal basis of the acceptance of pain alleviation with life-shortening effect can be found on the grounds of necessity. In different countries physicians have been prosecuted because of their pain management, which to the public prosecutor was in fact a sort of euthanasia. On the other hand, it is not unknown that physicians administer opioids to mask euthanasia. Pain management needs some rules, which can reassure the physician who alleviates pain. The physician who alleviates pain with life-shortening effect will have to act with due care to avoid a liability risk. This implies at least an informed consent, to observe the proportionality rule, and to keep a medical record.
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Archives of Disease in Childhood 2008 December; 93(12): 1067-1070

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Improving palliative care in Africa [editorial]
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Florence S. Wald, American pioneer in end-of-life care, is dead at 91 [obituary]

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Thinking about the best life in end-of-life care and neuroethics
Rinsho shinkeigaku = Clinical neurology 2008 November; 48(11): 955-957

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Ethics does not solve issues of ALS care, but palliative care does.
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Venke Gran, Siv; Miller, Jean

Norwegian nurses' thoughts and feelings regarding the ethics of palliative sedation.

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Bush, Tony; Bruni, Nina

Spiritual care as a dimension of holistic care: a relational interpretation.
International Journal of Palliative Nursing 2008 November; 14(11): 539-545

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Kantor, Debra P.

Caring for the dying patient

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Bullard, Tracy

A time for everything: a nurse comforts a dying patient's family
AJN: American Journal of Nursing 2008 November; 108(11): 72AAA

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American College of Emergency Physicians

Ethical issues at the end of life.
Annals of Emergency Medicine 2008 November; 52(5): 592

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Krakauer, Eric L.

**Just palliative care: responding responsibly to the suffering of the poor.**
Journal of Pain and Symptom Management 2008 November; 36(5): 505-512

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**Palliative care and social justice.**

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Gwyther, Liz

**Just palliative care? Integrated models of care.**
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Hastings Center Report 2008 November-December; 38(6): 7-8

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Vitello, Paul

**Hospices use more chaplains and new path toward secular**

[http://www.nytimes.com](http://www.nytimes.com) (link may be outdated)
Hospices use more chaplains and new path toward secular


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Dying from dementia – a patient's journey

Dartington, Tim

BMJ: British Medical Journal 2008 October 18; 337(7675): 931-933

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The kindness of strangers

Palmer, Eileen

BMJ: British Medical Journal 2008 October 11; 337(7674): 877

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Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups

Shipman, Cathy; Gysels, Marjolein; White, Patrick; Worth, Allison; Murray, Scott A.; Barclay, Stephen; Forrest, Sarah; Shepherd, Jonathan; Dale, Jeremy; Dewar, Steve; Peters, Marilyn; White, Suzanne; Richardson, Alison; Lorenz, Karl; Koffman, Jonathan; Higginson, Irene J.

BMJ: British Medical Journal 2008 October 11; 337(7674): 848-851

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Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment

Wright, Alexi A.; Zhang, Baohui; Ray, Alaka; Mack, Jennifer W.; Trice, Elizabeth; Balboni, Tracy; Mitchell, Susan L.; Jackson, Vicki A.; Block, Susan D.; Maciejewski, Paul K.; Prigerson, Holly G.

JAMA: Journal of the American Medical Association 2008 October 8; 300(14): 1665-1673

Abstract: CONTEXT: Talking about death can be difficult. Without evidence that end-of-life discussions improve patient outcomes, physicians must balance their desire to honor patient autonomy against a concern of inflicting psychological harm. OBJECTIVE: To determine whether end-of-life discussions with physicians are associated with fewer aggressive interventions. DESIGN, SETTING, AND PARTICIPANTS: A US multisite, prospective, longitudinal cohort study of patients with advanced cancer and their informal caregivers (n = 332 dyads), September 2002-February 2008. Patients were followed up from enrollment to death, a median of 4.4 months later. Bereaved caregivers' psychiatric illness and quality of life was assessed a median of 6.5 months later. MAIN OUTCOME MEASURES: Aggressive medical care (eg, ventilation, resuscitation) and hospice in the final week of life.
Secondary outcomes included patients' mental health and caregivers' bereavement adjustment. RESULTS: One hundred twenty-three of 332 (37.0%) patients reported having end-of-life discussions before baseline. Such discussions were not associated with higher rates of major depressive disorder (8.3% vs 5.8%; adjusted odds ratio [OR], 1.33; 95% confidence interval [CI], 0.54-3.32), or more worry (mean McGill score, 6.5 vs 7.0; \( P = .19 \)). After propensity-score weighted adjustment, end-of-life discussions were associated with lower rates of ventilation (1.6% vs 11.0%; adjusted OR, 0.26; 95% CI, 0.08-0.83), resuscitation (0.8% vs 6.7%; adjusted OR, 0.16; 95% CI, 0.03-0.80), ICU admission (4.1% vs 12.4%; adjusted OR, 0.35; 95% CI, 0.14-0.90), and earlier hospice enrollment (65.6% vs 44.5%; adjusted OR, 1.65; 95% CI, 1.04-2.63). In adjusted analyses, more aggressive medical care was associated with worse patient quality of life (6.4 vs 4.6; \( F = 3.61, P = .01 \)) and higher risk of major depressive disorder in bereaved caregivers (adjusted OR, 3.37; 95% CI, 1.12-10.13), whereas longer hospice stays were associated with better patient quality of life (mean score, 5.6 vs 6.9; \( F = 3.70, P = .01 \)). Better patient quality of life was associated with better caregiver quality of life at follow-up (beta = .20; \( P = .001 \)). CONCLUSIONS: End-of-life discussions are associated with less aggressive medical care near death and earlier hospice referrals. Aggressive care is associated with worse patient quality of life and worse bereavement adjustment.

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*Cancer and bioethics: caring and consensus.*

*Cancer* 2008 October 1; 113(7 Suppl): 1801-1806

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Schou, Kirsten; Alvsvåg, Herdis; Blåka, Gunnhild; Gjengedal, Eva

*The (dis)appearance of the dying patient in generalist hospital and care home nurses' talk about the patient*  
*Nursing Philosophy* 2008 October; 9(4): 233-247

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Steinberg, Avraham

*The Halachic basis of "The Dying Patient Law"*  
*Jewish Medical Ethics and Halacha* 2008 October; 6(2): 30-40

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Ravitsky, Vardit; Prawer, Michael

*The dying patient law, 2005*  
*Jewish Medical Ethics and Halacha* 2008 October; 6(2): 13-29

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Imhof, Sara L.; Kaskie, Brian
Promoting a "good death": determinants of pain-management policies in the United States

Abstract: Many Americans do not experience a good death. The inadequate treatment of pain at the end of life has been associated with a lack of supportive public policies more than a lack of evidence-based clinical practices or organizational efforts. Given a widespread lack of understanding about pain policies, we examine the critical role played by state medical boards in developing pain policies and then apply event history analysis to identify the variables most critical to the formation of these policies. We develop an integrated model and evaluate the adoption of eight different types of pain policies. The analytic models incorporate fifteen years of observational data and test the impact of contextual, political, extrinsic, and institutional variables. They reveal that the presence of legal counselors on state medical boards has consistently increased the likelihood that state boards adopt policies associated with progressive pain management. Further, policy has been negatively influenced by historical activity: boards that previously adopted one pain policy have been less likely to subsequently adopt additional pain policies. This work illuminates mechanisms behind state pain-policy adoption and provides valuable information for advocates who seek to improve pain-management policy and reduce the amount of pain at the end of life.

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Comfort measures only.
Journal of General Internal Medicine 2008 October; 23(10): 1720-1721

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Care for patients in the last months of life: the Belgian Sentinel Network Monitoring End-of-Life Care study
Archives of Internal Medicine 2008 September 8; 168(16): 1747-1754

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Making it work: utilizing the tripartite First Nations Health Plan to enhance palliative care service to First Nations communities [abstract]
Journal of Palliative Care 2008 Autumn; 24(3): 221

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Lest we forget [abstract]
Journal of Palliative Care 2008 Autumn; 24(3): 221
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Schwartz, Karen; Lutfiyya, Zana Marie
Facilitating dignity conserving care for people with intellectual disabilities [abstract]
Journal of Palliative Care 2008 Autumn; 24(3): 219

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Giving information to Latino and Chinese families in pediatric palliative care [abstract]
Journal of Palliative Care 2008 Autumn; 24(3): 214

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Vachon, Mélanie; Fillion, Lise; Achille, Marie
A conceptual analysis of spiritual and existential issues in palliative care [abstract]
Journal of Palliative Care 2008 Autumn; 24(3): 208

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Gallagher, Romayne; Koning, Fred; Vanderbijl, Ann
Healthcare providers' knowledge of ethics, diversity, and end-of-life issues: serious gaps of knowledge that could affect care [abstract]
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Janvier, Annie; Verhagen, Eduard A.A.; Leuthner, Steven; Meadow, William
The use of palliative care medication in the NICU at the time of death: a cross-cultural study in the USA, Canada, and the Netherlands [abstract]
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District nurses’ attitudes toward patient consent: the case of mechanical ventilation on amyotrophic lateral sclerosis patients: results from a French national survey.
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From ethics to palliative care: a community hospital experience
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*Dignity matters: advance care planning for people experiencing homelessness*

Journal of Clinical Ethics 2008 Fall; 19(3): 214-222

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Douglas, Charles; Kerridge, Ian; Ankeny, Rachel

*Managing intentions: the end-of-life administration of analgesics and sedatives, and the possibility of slow euthanasia*

Bioethics 2008 September; 22(7): 388-396

**Abstract:** There has been much debate regarding the 'double-effect' of sedatives and analgesics administered at the end-of-life, and the possibility that health professionals using these drugs are performing 'slow euthanasia.' On the one hand, analgesics and sedatives can do much to relieve suffering in the terminally ill. On the other hand, they can hasten death. According to a standard view, the administration of analgesics and sedatives amounts to euthanasia when the drugs are given with an intention to hasten death. In this paper we report a small qualitative study based on interviews with 8 Australian general physicians regarding their understanding of intention in the context of questions about voluntary euthanasia, assisted suicide and particularly the use of analgesic and sedative infusions (including the possibility of voluntary or non-voluntary 'slow euthanasia'). We found a striking ambiguity and uncertainty regarding intentions amongst doctors interviewed. Some were explicit in describing a 'grey' area between palliation and euthanasia, or a continuum between the two. Not one of the respondents was consistent in distinguishing between a foreseen death and an intended death. A major theme was that 'slow euthanasia' may be more psychologically acceptable to doctors than active voluntary euthanasia by bolus injection, partly because the former would usually only result in a small loss of 'time' for patients already very close to death, but also because of the desirable ambiguities surrounding causation and intention when an infusion of analgesics and sedatives is used. The empirical and philosophical implications of these findings are discussed.

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Battin, Margaret P.

*Terminal sedation: pulling the sheet over our eyes*


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**Document 439**

Wolf, Susan M.

*Confronting physician-assisted suicide and euthanasia: my father's death*


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Astrow, A.B.; Sood, J.R.; Nolan, M.T.; Terry, P.B.; Clawson, L.; Kub, J.; Hughes, M.; Sulmasy, D.P.

*Decision-making in patients with advanced cancer compared with amyotrophic lateral sclerosis*
Abstract: Aim: Patients with advanced cancer need information about end-of-life treatment options in order to make informed decisions. Clinicians vary in the frequency with which they initiate these discussions. Patients and methods: As part of a long-term longitudinal study, patients with an expected 2-year survival of less than 50% who had advanced gastrointestinal or lung cancer or amyotrophic lateral sclerosis (ALS) were interviewed. Each patient’s medical record was reviewed at enrollment and at 3 months for evidence of the discussion of patient wishes concerning ventilator support, artificial nutrition and hydration (ANH), resuscitation (DNR) and hospice care. A Kaplan–Meier analysis was also performed and 2-year survival calculated. Results: 60 cancer and 32 ALS patients were enrolled. ALS patients were more likely than cancer patients to have evidence of discussion about their wishes for ventilator support (31% vs 0%, p<0.001), ANH (38% vs 0%, p<0.001), DNR (25% vs 0%, p<0.001) and hospice care (22% vs 5%, p = 0.03). At 6 months, 91% of ALS patients were alive compared with 62% of cancer patients; at 2 years, 63% of ALS patients were alive compared with 23% of cancer patients (p<0.001). Conclusions: Cancer patients were less likely than ALS patients to have had documented advanced care planning discussions despite worse survival. This may reflect perceptions that ALS has a more predictable course, that advanced cancer has a greater number of treatment options, or differing views about hope. Nevertheless, cancer patients may be less adequately prepared for end-of-life decision-making.

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McClave, Stephen A.; Delegge, Mark H.

*Predicting life expectancy before percutaneous endoscopic gastrostomy placement: a lesson in futility or an exercise of injustice?*

Gastrointestinal Endoscopy 2008 August; 68(2): 228-230, quiz 333, 335

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Wasserman, Linda S.

*Respectful death: a model for end-of-life care.*


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Chaturvedi, S.K.

*Ethical dilemmas in palliative care in traditional developing societies, which special reference to the Indian setting*

Journal of Medical Ethics 2008 August; 34(8): 611-615

**Abstract:** Background: There are intriguing and challenging ethical dilemmas in the practice of palliative care in a traditional developing society. Objective: To review the different ethical issues involved in cancer and palliative care in developing countries, with special reference to India. Methods: Published literature on pain relief and palliative care in the developing countries was reviewed to identify ethical issues and dilemmas related to these, and ways in which ethical principles could be observed in delivery of palliative care in such countries are discussed. Results: The literature review revealed a number of ethical dilemmas and challenges that professionals, cancer patients and their families encountered during palliative care. It was noted that patients’ preferences and decisions are influenced by family members. Dilemmas leave the professionals and families confused about how ethical their actions have been. Specific ethical issues were noted in relation to the availability and use of oral morphine for pain relief, spiritual care, lack of adequate palliative care services, and palliative care education. Conclusions: The four principles of ethics posed difficulties in understanding the complex ethical issues in a developing country with a traditional background. Ethical issues need to be handled delicately and sensitively in palliative care settings, within the framework of the traditions and culture of the society and financial constraints. The possible role of ethics committees in palliative care settings to help decision-making needs to be studied and discussed.

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*The good death [editorial]*

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End of life strategy offers home based nursing care 24 hours a day for dying patients [news]
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The pursuit of happiness in end-of-life care [editorial]
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Psycho-oncology 2008 July; 17(7): 641-659
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**Red towels: maximizing the care of patients who are dying**

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Dealing with delicate issues in continuous deep sedation: varying practices among Dutch medical specialists, general practitioners, and nursing home physicians

Archives of Internal Medicine 2008 March 10; 168(5): 537-543

Abstract: BACKGROUND: This article examines delicate issues in continuous deep sedation (CDS) from the perspectives of different types of physicians. The following sensitive issues involved in CDS were investigated: artificial hydration, sedation for nonphysical discomfort, the relationship between CDS and euthanasia, and patient involvement in decision making for CDS. METHODS: A structured retrospective questionnaire concerning the most recent case of CDS during the past 12 months was sent to a sample of medical specialists (n = 727), general practitioners (n = 626), and nursing home physicians (n = 111). RESULTS: Response rates were 26.4% for medical specialists, 37.4% for general practitioners, and 59.5% for nursing home physicians. Indications for CDS differed among the types of physicians. General practitioners (25.0%) were most often confronted with a patient request for euthanasia before starting CDS compared with medical specialists (8.9%) and nursing home physicians (6.5%). A decision to forgo artificial hydration in CDS was more often made by nursing home physicians (91.3%) compared with medical specialists (53.7%) and general practitioners (51.2%). Shorter survival was found for patients sedated for nonphysical discomfort (vs other patients) by general practitioners. Among all patients, 74.5% were involved in decision making before the start of CDS. CONCLUSIONS: The present study demonstrates notable differences in CDS practice among various types of physicians. To what extent this is related to different patient populations or to different expertise requires further investigation. The use of CDS for nonphysical discomfort calls for critical examination to avoid ambiguous practice.

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Mundy, Liza

The vow: when Dave Kendall promised to love Diana "in sickness and in health," he meant it

Washington Post Magazine 2008 March 9; p. 11-15, 23-28

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Liben, Stephen; Papadatou, Danai; Wolfe, Joanne

Paediatric palliative care: challenges and emerging ideas

Lancet 2008 March 8-14; 371(9615): 852-864

Abstract: Paediatric palliative care is an emerging subspecialty that focuses on achieving the best possible quality of life for children with life-threatening conditions and their families. To achieve this goal, the individuals working in this field need to: clearly define the population served; better understand the needs of children with life-threatening conditions and their families; develop an approach that will be appropriate across different communities; provide care that responds adequately to suffering; advance strategies that support caregivers and health-care providers; and promote needed change by cultivating educational programmes. Despite these challenges, advances in paediatric palliative care have been achieved in a short period of time; we expect far greater progress as the field becomes more formalised and research networks are established.

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Paediatric palliative care [editorial]

Lancet 2008 March 8-14; 371(9615): 786
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Antibiotics questioned in care at life's end

Stephens, Sheila

Hospital-based palliative care: cost-effective care for patients with advanced disease
The Journal of Nursing Administration 2008 March; 38(3): 143-145

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Sterben in würde [Dying in dignity]

Ens, Carla D.L.; Chochinov, Harvey M.; Bérard, Josette L.M.; Harlos, Mike S.; Stenekes, Simone J.; Wowchuk, Suzanne M.

Pediatric palliative care online: the views of health care professionals
Journal of Palliative Care 2008 Spring; 24(1): 41-48

St-Laurent-Gagnon, Thérèse; Carnevale, Franco A.; Duval, Michel

Pediatric palliative care: a qualitative study of physicians' perspectives in a tertiary care university hospital
Journal of Palliative Care 2008 Spring; 24(1): 26-30

Thompson, Genevieve N.; Chochinov, Harvey M.

Dignity-based approaches in the care of terminally ill patients.
Current Opinion in Supportive and Palliative Care 2008 March; 2(1): 49-53
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Sinuff, Tasnim; Cook, Deborah J.; Keenan, Sean P.; Bums, Karen E.A.; Adhikari, Neill K.J.; Rocker, Graeme M.; Mehta, Sangeeta; Kacmarek, Robert; Eva, Kevin; Hill, Nicholas S.
**Noninvasive ventilation for acute respiratory failure near the end of life.**
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Journal of Palliative Medicine 2008 March; 11(2): 138-139

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**Promoting a “good death”: determinants of pain management in the United States [abstract]**
National Catholic Bioethics Quarterly 2008 Spring; 8(1): 179-180

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**Decision-making capacity in terminally ill cancer patients [abstract]**
National Catholic Bioethics Quarterly 2008 Spring; 8(1): 176

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Thacker, Karen S.
**Nurses’ advocacy behaviors in end-of-life nursing care**
Nursing Ethics 2008 March; 15(2): 174-185

**Abstract:** Nursing professionals are in key positions to support end-of-life decisions and to advocate for patients and families across all health care settings. Advocacy has been identified as the common thread of quality end-of-life nursing care. The purpose of this comparative descriptive study was to reveal acute care nurses’ perceptions of advocacy behaviors in end-of-life nursing practice. The 317 participating nurses reported frequent contact with dying patients despite modest exposure to end-of-life education. This study did not confirm an overall difference in advocacy behaviors among novice, experienced and expert nurses; however, it offered insight into the supports and barriers nurses at different skill levels experienced in their practice of advocacy.

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Cellarius, Victor

*Terminal sedation and the “imminence condition”*

Journal of Medical Ethics 2008 February; 34(2): 69-72

Abstract: "Terminal sedation" refers to the use of sedation as palliation in dying patients with a terminal diagnosis. Although terminal sedation has received widespread legal and ethical justification, the practice remains ethically contentious, particularly as some hold that it foreseeably hastens death. It has been proposed that empirical studies show that terminal sedation does not hasten death, or that even if it may hasten death it does not do so in a foreseeable way. Nonetheless, it is clear that providing terminal sedation in combination with the withholding or withdrawing of life-prolonging treatments such as fluid and nutrition can foreseeably hasten death significantly—what is here called early terminal sedation (ETS). There are ethical justifications for the use of sedation in palliative care and thus it would seem that ETS is an ethically and legally acceptable practice. However, what emerges from the literature is the repeated assertion that terminal sedation must be restricted to use in imminently dying patients—the "imminence condition"—and that therefore ETS is unacceptable. This restriction has taken on greater significance with the trend of palliative care to include the care of patients who are not imminently dying. This paper proposes to show that although there is widespread intuitive support for the imminence condition, it does not follow from the justifications for sedation as palliation, and that explicit arguments for the imminence condition are needed.

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Johnson, Kimberly S.; Kuchibhatla, Maragatha; Tanis, David; Tulsky, James A.

*Racial differences in hospice revocation to pursue aggressive care*

Archives of Internal Medicine 2008 January 28; 168(2): 218-224

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Berry, Scott R.

*Just say die*

Journal of Clinical Oncology 2008 January 1; 26(1): 157-159

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Sprung, Charles L.; Ledoux, Didier; Bulow, Hans-Henrik; Lippert, Anne; Wennberg, Elisabet; Baras, Mario; Ricou, Bara; Sjovkist, Peter; Wallis, Charles; Maia, Paulo; Thijs, Lambertius G.; Solsona Duran, Jose

**Relieving suffering or intentionally hastening death: where do you draw the line?**
Critical Care Medicine 2008 January; 36(1): 8-13

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**Palliative sedation as part of a continuum of palliative care.**
Journal of Palliative Medicine 2008 January-February; 11(1): 76-81

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**Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home.**
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**Spiritual care at the end of life in long-term care**
Medical Care 2008 January; 46(1); 85-91

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Call number: R726.8 .N93 2008

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COMMUNICATION AS COMFORT: MULTIPLE VOICES IN PALLIATIVE CARE
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**Balancing autonomy and traditional values in treating terminally ill patients: towards locating the right questions for Japan**
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**Death and dying in the US: the barriers to the benefits of palliative and hospice care.**
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**Palliative sedation until death: an approach from Kant's ethics of virtue.**
Theoretical Medicine and Bioethics 2008; 29(6): 387-396
**Abstract:** This paper is concerned with the moral justification for palliative sedation until death. Palliative sedation involves the intentional lowering of consciousness for the relief of untreatable symptoms. The paper focuses on the moral problems surrounding the intentional lowering of consciousness until death itself, rather than possible adjacent life-shortening effects. Starting from a Kantian perspective on virtue, it is shown that continuous deep sedation until death (CDS) does not conflict with the perfect duty of moral self-preservation because CDS does not destroy capacities for agency. In addition, it is argued that CDS can frustrate the imperfect duty of self-cultivation by reducing consciousness permanently. Nevertheless, there are cases where CDS is morally acceptable, namely,
cases where the agent has already permanently lost the possibility for free action in advance of sedation—for example, due to excruciating and ongoing pain. Because the latter can be difficult to diagnose properly, safeguards may be needed in order to prevent the application of CDS for the wrong reasons.

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*Hospice care: when the dying live on [letters]*

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*ACT -- for pediatric palliative care*
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*Autonomy, human dignity, and death with dignity: advancing a relational view of human dignity in end-of-life bioethics [dissertation abstract]*
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From cure to palliation: concept, decision and acceptance
Journal of Medical Ethics 2007 December; 33(12): 685-688

Abstract: The aim of this paper is to present and discuss nurses' and physicians' comments in a questionnaire relating to patients' transition from curative treatment to palliative care. The four-page questionnaire relating to experiences of and attitudes towards communication, decision-making, documentation and responsibility of nurses and physicians and towards the competence of patients was developed and sent to a random sample of 1672 nurses and physicians of 10 specialties. The response rate was 52% (n = 844), and over one-third made comments. The respondents differed in their comments about three areas: the concept of palliative care, experiences of unclear decision-making and difficulties in acceptance of the patient's situation. The responses are analysed in terms of four ethical theories: virtue ethics, deontology, consequentialism and casuistry. Many virtues considered to be appropriate for healthcare personnel to possess were invoked. Compassion, honesty, justice and prudence are especially important. However, principles of medical ethics, such as the deontological principle of respect for self-determination and the consequence of avoidance of harm, are also implied. Casuistry may be particularly helpful in analysing certain areas of difficulty—namely, what is meant by "palliative care", decision-making and accepting the patient's situation. Keeping a patient in a state of uncertainty often causes more suffering than necessary. Communication among the staff and with patients must be explicit. Many of the staff have not had adequate training in communicating with patients who are at the end of their life. Time for joint reflection has to be regained, and training in decision-making is essential. In our opinion, palliative care in Sweden is in need of improvement.

In hospice care, longer lives mean money lost

Appropriate discontinuation of medications at the end of life: a need to establish consensus criteria.
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*Cancer control: knowledge into action; WHO guide for effective programmes: Palliative Care*

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Palliative care for prison inmates: “don’t let me die in prison”
Abstract: The number of older inmates in US correctional facilities is increasing and with it the need for quality care...
palliative health care services. Morbidity and mortality are high in this population. Palliative care in the correctional setting includes most of the challenges faced in the free-living community and several unique barriers to inmate care. Successful models of hospice care in prisons have been established and should be disseminated and evaluated. This article highlights why the changing demographics of prison populations necessitates hospice in this setting and highlights many of the barriers that correctional and consulting physicians face while providing palliative care. Issues specific to palliative care and hospice in prison include palliative care standards, inmate-physician and inmate-family relationships, confidentiality, interdisciplinary care, do-not-resuscitate orders and advance medical directives, medical parole, and the use of inmate volunteers in prison hospice programs. We also include practical recommendations to community-based physicians working with incarcerated or recently released prisoners and describe solutions that can be implemented on an individual and systems basis.

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Characteristics of deaths occurring in hospitalised children: changing trends
Journal of Medical Ethics 2007 May; 33(5): 255-260
Abstract: BACKGROUND: Despite a gradual shift in the focus of medical care among terminally ill patients to a palliative model, studies suggest that many children with life-limiting chronic illnesses continue to die in hospital after prolonged periods of inpatient admission and mechanical ventilation. OBJECTIVES: To (1) examine the characteristics and location of death among hospitalised children, (2) investigate yearwise trends in these characteristics and (3) test the hypothesis that professional ethical guidance from the UK Royal College of Paediatrics and Child Health (1997) would lead to significant changes in the characteristics of death among hospitalised children. METHODS: Routine administrative data from one large tertiary-level UK children's hospital was examined over a 7-year period (1997-2004) for children aged 0-18 years. Demographic details, location of deaths,
source of admission (within hospital vs external), length of stay and final diagnoses (International Classification of Diseases-10 codes) were studied. Statistical significance was tested by the Kruskal-Wallis analysis of ranks and median test (non-parametric variables), chi(2) test (proportions) and Cochran-Armitage test (linear trends).

RESULTS: Of the 1127 deaths occurring in hospital over the 7-year period, the majority (57.7%) were among infants. The main diagnoses at death included congenital malformations (22.2%), perinatal diseases (18.1%), cardiovascular disorders (14.9%) and neoplasms (12.4%). Most deaths occurred in an intensive care unit (ICU) environment (85.7%), with a significant increase over the years (80.1% in 1997 to 90.6% in 2004). There was a clear increase in the proportion of admissions from in-hospital among the ICU cohort (14.8% in 1998 to 24.8% in 2004). Infants with congenital malformations and perinatal conditions were more likely to die in an ICU (OR 2.42, 95% CI 1.65 to 3.55), and older children with malignancy outside the ICU (OR 6.5, 95% CI 4.4 to 9.6). Children stayed for a median of 13 days interquartile range 4.0-23.25 days) on a hospital ward before being admitted to an ICU where they died.

CONCLUSIONS: A greater proportion of hospitalised children are dying in an ICU environment. Our experience indicates that professional ethical guidance by itself may be inadequate in reversing the trends observed in this study.

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A communication strategy and brochure for relatives of patients dying in the ICU


Abstract: BACKGROUND: There is a need for close communication with relatives of patients dying in the intensive care unit (ICU). We evaluated a format that included a proactive end-of-life conference and a brochure to see whether it could lessen the effects of bereavement. METHODS: Family members of 126 patients dying in 22 ICUs in France were randomly assigned to the intervention format or to the customary end-of-life conference. Participants were interviewed by telephone 90 days after the death with the use of the Impact of Event Scale (IES; scores range from 0, indicating no symptoms, to 75, indicating severe symptoms related to post-traumatic stress disorder [PTSD]) and the Hospital Anxiety and Depression Scale (HADS; subscale scores range from 0, indicating no distress, to 21, indicating maximum distress). RESULTS: Participants in the intervention group had longer conferences than those in the control group (median, 30 minutes [interquartile range, 19 to 45] vs. 20 minutes [interquartile range, 15 to 30]; P<0.001) and spent more of the time talking (median, 14 minutes [interquartile range, 8 to 20] vs. 5 minutes [interquartile range, 5 to 10]). On day 90, the 56 participants in the intervention group who responded to the telephone interview had a significantly lower median IES score than the 52 participants in the control group (27 vs. 39, P=0.02) and a lower prevalence of PTSD-related symptoms (45% vs. 69%, P=0.01). The median HADS score was also lower in the intervention group (11, vs. 17 in the control group; P=0.004), and symptoms of both anxiety and depression were less prevalent (anxiety, 45% vs. 67%; P=0.02; depression, 29% vs. 56%; P=0.003). CONCLUSIONS: Providing relatives of patients who are dying in the ICU with a brochure on bereavement and using a proactive communication strategy that includes longer conferences and more time for family members to talk may lessen the burden of bereavement. (ClinicalTrials.gov number, NCT00331877.) 2007 Massachusetts Medical Society
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Ethical and practical issues with opioids in life-limiting illness.
Proceedings (Baylor University. Medical Center) 2007 Jan; 20(1): 5-12

Abstract: Effective pain relief, especially at the end of life, is a primary ethical obligation based upon the principles of beneficence, nonmaleficence, patient autonomy, and particularly the concept of double effect. The pragmatic foundation of pain management begins with a complete assessment, which incorporates "WILDA" (words, intensity, location, duration, aggravating/alleviating factors) and considers the components of total pain: physical, emotional, social, and spiritual pain. Opioids are the pharmacologic sine qua non of pain management in life-limiting illness and should be prescribed based on the severity of pain, considering the functional and psychological significance of that severity. Numerous misunderstandings present a barrier to effective pain management. These misconceptions include the idea that opioids are highly addictive, that dependence or tolerance are forms of addiction, that respiratory depression is common with opioids, that opioids have a narrow therapeutic range, and that opioids are ineffective by mouth and cause too much nausea. In reality, opioids are the safest and most effective pain medicine for most moderate to severe pain in most patients. Aspects of basic opioid pharmacology, such as dosage, route of administration, rotation of drugs, and the avoidance of toxicity and complications, should be considered when initiating and maintaining therapy. Failure to pay attention to the basic rules can lead to errors in opioid management.

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**Why hospice nurses need high self-esteem**

Nursing Ethics 2007 January; 14(1): 62-71

*Abstract:* This article discusses the relationship between personal and professional qualities in hospice nurses. We examine the notion of self-esteem in personal and professional identity. The focus is on two questions: (1) what is self-esteem, and how is it related to personal identity and its moral dimension? and (2) how do self-esteem and personal identity relate to the professional identity of nurses? We demonstrate it is important that the moral and personal goals in nurses' life coincide. If nurses' personal view of the good life is compatible with their experiences and feelings as professionals, this improves their performance as nurses. We also discuss how good nursing depends on the responses that nurses receive from patients, colleagues and family; they make nurses feel valued as persons and enable them to see the value of the work they do.

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**Palliative care in the U.S. healthcare system: Constitutional right or criminal act?**

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Kushel, Margot B.; Miaskowski, Christine

**End-of-life care for homeless patients: "she says she is there to help me in any situation"**

**Abstract:** Homelessness annually affects an estimated 2.3 million to 3.5 million individuals living in the United States. Homeless people face difficulties in meeting their basic needs. Many have substance abuse problems and mental illness, lack social support, and have no medical insurance. These challenges complicate the homeless patient's ability to engage in end-of-life advanced planning, adhere to medications, and find an adequate site to receive terminal care. Employing a multidisciplinary team to care for homeless patients can help address their needs and improve care. For patients who continue to use illicit substances while receiving end-of-life care, experts recommend scheduling frequent clinic visits, using long-acting pain medications, dispensing small quantities of medications at a time, and using a written pain agreement. Homeless people are less likely to have a surrogate decision maker. Clinicians should have frequent, well-documented conversations with these patients about end-of-life wishes. Homeless people can rarely use hospice services because they lack the financial resources for inpatient hospice and have neither the home nor the social support required for home hospice. Developing inpatient palliative care services at hospitals that serve many homeless people could improve the end-of-life care homeless people receive.

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hasten death (n = 123). We compared characteristics of the patients, the decision-making process, and medical care of both practices. RESULTS: Terminal sedation and euthanasia both mostly concerned patients with cancer. Patients receiving terminal sedation were more often anxious (37%) and confused (24%) than patients receiving euthanasia (15% and 2%, respectively). Euthanasia requests were typically related to loss of dignity and a sense of suffering without improving, whereas requesting terminal sedation was more often related to severe pain. Physicians applying terminal sedation estimated that the patient's life had been shortened by more than 1 week in 27% of cases, compared with 73% in euthanasia cases. CONCLUSIONS: Terminal sedation and euthanasia both are often applied to address severe suffering in terminally ill patients. However, terminal sedation is typically used to address severe physical and psychological suffering in dying patients, whereas perceived loss of dignity during the last phase of life is a major problem for patients requesting euthanasia.

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Factors influencing death at home in terminally ill patients with cancer; systematic review
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Abstract: OBJECTIVES: To determine the relative influence of different factors on place of death in patients with cancer. DATA SOURCES: Four electronic databases-Medline (1966-2004), PsycINFO (1972-2004), CINAHL (1982-2004), and ASSIA (1987-2004); previous contacts with key experts; hand search of six relevant journals. REVIEW METHODS: We generated a conceptual model, against which studies were analysed. Included studies had original
data on risk factors for place of death among patients, > 80% of whom had cancer. Strength of evidence was assigned according to the quantity and quality of studies and consistency of findings. Odds ratios for home death were plotted for factors with high strength evidence. RESULTS: 58 studies were included, with over 1.5 million patients from 13 countries. There was high strength evidence for the effect of 17 factors on place of death, of which six were strongly associated with home death: patients’ low functional status (odds ratios range 2.29-11.1), their preferences (2.19-8.38), home care (1.37-5.1) and its intensity (1.06-8.65), living with relatives (1.78-7.85), and extended family support (2.28-5.47). The risk factors covered all groups of the model: related to illness, the individual, and the environment (healthcare input and social support), the latter found to be the most important. CONCLUSIONS: The number of factors that influence where patients with cancer die is complicated. Future policies and clinical practice should focus on ways of empowering families and public education, as well as intensifying home care, risk assessment, and training practitioners in end of life care.

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Are patient preferences for life-sustaining treatment really a barrier to hospice enrollment for older adults with serious illness?

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**Meeting palliative care needs in post-acute care settings: "to help them live until they die"**

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**Drugs used to alleviate symptoms with life shortening as a possible side effect: end-of-life care in six European countries**
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"Nobody understands": on a cardinal phenomenon of palliative care

Abstract: In the clinical practice of palliative medicine, recommended communication models fail to approximate the truth of suffering associated with an impending death. I provide evidence from patients' stories and empiric research alike to support this observation. Rather than attributing this deficiency to inadequate training or communication skills, I examine the epistemological premises of the biomedical language governing the patient-physician communication. I demonstrate that the contemporary biomedicine faces a fundamental aporetic occlusion in attempting to examine death. This review asserts that the occlusion defines, rather than simply complicating, palliative care. Given the defining place of aporia in the care for the dying, I suggest that this finding shape the clinicians' responses to the needs of patients in clinical care and in designing palliative research. Lastly, I briefly signal that a genuinely apophatic voice construing the occlusion as a mystery rather than an aporia may be superior to the present communication and empathy models.

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Nurses' perceptions of quality of end-of-life care on an acute medical ward

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Providing a "good death": critical care nurses' suggestions for improving end-of-life care

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The caring relationship in hospice care: an analysis based on the ethics of the caring conversation

Olthuis, Gert; Dekkers, Wim; Leget, Carlo; Vogelaar, Paul

Abstract: Good nursing is more than exercising a specific set of skills. It involves the personal identity of the nurse. The aim of this article is to answer two questions: (1) what kind of person should the hospice nurse be? and (2) how should the hospice nurse engage in caring conversations? To answer these questions we analyse a nurse's story that is intended to be a profile of an exemplary hospice nurse. This story was constructed from an analysis of five semistructured interviews with hospice nurses, based on the 'ethics of the caring conversation', which is inspired by the ethical perspective of Paul Ricoeur. The research questions concentrate on the norms of respect, responsibility and reciprocity, which are integral parts of the 'ethics of the caring conversation'.

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**Correspondence between patients' preferences and surrogates' understandings for dying and death**

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**Exploration of the decision-making process for inpatient hospice admissions**
Abstract: Practitioners of palliative care often argue for more resources to be provided by the state in order to lessen its reliance on charitable funding and to enable the services currently provided to some of those with terminal illnesses to be provided to all who would benefit from it. However, this is hard to justify on grounds of cost-effectiveness, since it is in the nature of palliative care that the benefits it brings to its patients are of short duration. In particular, palliative care fares badly under a policy of QALY-maximisation, since procedures which prevent premature death (provided the life is of reasonable quality) or improve quality of life for those with longer life expectancy will produce more QALYs. This paper examines various responses to this problem and argues that in order to justify increased resources for palliative care its advocates must reject the 'atomistic' view of the value of life implicit in the QALY approach in favour of a 'holistic' or 'narrative' account. This, however, has implications which advocates of palliative care may be reluctant to embrace.
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Abstract: Despite skilled palliative care, some dying patients experience distressing symptoms that cannot be adequately relieved. A patient with metastatic breast cancer, receiving high doses of opioids administered to relieve pain, developed myoclonus. After other approaches proved ineffective, palliative sedation was an option of last resort. The doctrine of double effect, the traditional justification for palliative sedation, permits physicians to provide high doses of opioids and sedatives to relieve suffering, provided that the intention is not to cause the patient's death and that certain other conditions are met. Such high doses are permissible even if the risk of hastening death is foreseen. Because intention plays a key role in this doctrine, clinicians must understand and document which actions are consistent with an intention to relieve symptoms rather than to hasten death. The patient or family should agree with plans for palliative sedation. The attending physician needs to explain to them, as well as to the medical and nursing staff, the details of care and the justification for palliative sedation. Because cases involving palliative sedation are emotionally stressful, the patient, family, and health care workers can all benefit from talking about the complex medical, ethical, and emotional issues they raise.
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**End-of-life care and family involvement [letter]**

Journal of the American Geriatrics Society 2004 June; 52(6): 1027-1028

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Tokuda, Y.; Nakazato, N.; Tamaki, K.

**Evaluation of end of life care in cancer patients at a teaching hospital in Japan**

Journal of Medical Ethics 2004 June; 30(3): 264-267

**Abstract:** OBJECTIVES: To analyse the decision making for end of life care for patients with cancer at a teaching hospital in Japan at two periods 10 years apart. DESIGN AND SETTING: Retrospective study conducted in a 550 bed community teaching hospital in Okinawa, Japan. PATIENTS: There were 124 terminally ill cancer patients (45 women; 79 men; median age, 69 years) admitted either in 1989 and 1999 for end of life care with sufficient data to permit analysis. Main measurements: Basic demographic data, notification to the patient that he or she had cancer, patient involvement in do not resuscitate (DNR) orders, and various medical interventions which were performed in the month prior to the patient's death were evaluated. RESULTS: In 1989 none of the patients were notified of their diagnosis; in 1999 five patients were informed (p = 0.026). Of the 113 (91%) patients with a written DNR order, none were involved in consenting to the DNR order. In the month before death, patients in both groups received non-palliative treatments such as feeding tube placements (five in 1989; five in 1999), total parenteral nutrition (six in 1989; eight in 1999), and intravenous albumin infusion (four in 1989; five in 1999). Morphine use increased (30%) significantly in 1999 compared with the 1989 group. CONCLUSIONS: The majority of patients dying of cancer were still not informed of their diagnosis and were seldom involved in DNR decision making at a teaching hospital in Japan. There was no change in the number of potentially futile interventions that were performed (6-13%) but morphine use increased. Modern ethical education is urgently needed in Japanese medical practice to improve decision making process in the end of life care.

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**Editorial: death, dying, and bereavement**

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Quill, Timothy E.
**Dying and decision making -- evolution of end-of-life options**
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**The challenge of discrepancies in values among physicians, patients, and family members [editorial]**
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Journal of the American College of Surgeons 2004 May; 198(5): 837-841
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Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States

Abstract: OBJECTIVE: To evaluate the use of healthcare resources during the last six months of life among patients of US hospitals with strong reputations for high quality care in managing chronic illness. DESIGN: Retrospective cohort study based on claims data from the US Medicare programme. PARTICIPANTS: Cohorts receiving most of their hospital care from 77 hospitals that appeared on the 2001 US News and World Report "best hospitals" list for heart and pulmonary disease, cancer, and geriatric services. MAIN OUTCOME MEASURES: Use of healthcare resources in the last six months of life: number of days spent in hospital and in intensive care units; number of physician visits; percentage of patients seeing 10 or more physicians; percentage enrolled in hospice. Terminal care: percentage of deaths occurring in hospital; percentage of deaths occurring in association with a stay in an intensive care unit. RESULTS: Extensive variation in each measure existed among the 77 hospital cohorts. Days in hospital per decedent ranged from 9.4 to 27.1 (interquartile range 11.6-16.1); days in intensive care units ranged from 1.6 to 9.5 (2.6-4.9); number of physician visits ranged from 17.6 to 76.2 (25.5-39.5); percentage of patients seeing 10 or more physicians ranged from 16.9% to 58.5% (29.4-43.4%); and hospice enrollment ranged from 10.8% to 43.8% (22.0-32.0%). The percentage of deaths occurring in hospital ranged from 15.9% to 55.6% (35.4-43.1%), and the percentage of deaths associated with a stay in intensive care ranged from 8.4% to 36.8% (20.2-27.1%). CONCLUSION: Striking variation exists in the utilisation of end of life care among US medical centres with strong national reputations for clinical care.

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**Overcoming the false dichotomy of "curative" vs "palliative" care for late-stage HIV/AIDS: "let me live the way I want to live, until I can't" [opinion]**


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


**Abstract:** Even for patients receiving complex, intensive medical care for serious and life-threatening illness, family caregiving is typically at the core of what sustains patients at the end of life. The amorphous relationship between physicians and the families of patients at the end of life presents both challenges and opportunities for which physicians may be unprepared. Families play important roles in the practical and emotional aspects of patient care and in decision making at the end of life. At the same time, family members may carry significant burdens as a result of their work. Through the perspectives of the wife, daughter, and home care nurse of a patient who died from pancreatic cancer, we illustrate the range of family caregiver experiences and suggest potentially helpful physician interventions. We describe 5 burdens of family caregiving (time and logistics, physical tasks, financial costs, emotional burdens and mental health risks, and physical health risks) and review the responsibilities of physicians to family caregivers. Based on available evidence, we identify 5 areas of opportunity for physicians to be of service to family members caring for patients at the end of life, including promoting excellent communication with family, encouraging appropriate advance care planning and decision making, supporting home care, demonstrating empathy for family emotions and relationships, and attending to family grief and bereavement. In caring well for family caregivers at the end of life, physicians may not only improve the experiences of patients and family but also find
greater sustenance and meaning in their own work.

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Completing the Continuum of ALS Care: A Consensus Document

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Abstract: Reflects on the change in Western attitudes toward death and end-of-life care brought about over the last four decades through the efforts of four visionary healthcare professionals. Dame Cicely Saunders, nurse, social worker, and physician, founded the modern hospice movement in England by founding St. Christopher's Hospice in 1967. Florence Wald, professor of nursing and former Dean of the Yale University School of Nursing, founded the first hospice in the United States in 1974. Elisabeth Kubler-Ross, psychiatrist and founder of the Death with Dignity movement, brought about great changes in understanding of the dying process with her 1969 book, On Death and Dying. Balfour Mount, physician, is considered the founder of palliative care in Canada. He was the Founding Director of the Royal Victoria Hospital Palliative Care Service at McGill University in 1974. [description details adapted from the Fanlight site]

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**The principle of double effect and pain medication**

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**Preparing for dying: meaningful practices in palliative care**
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**Examining ethical dilemmas as obstacles to hospice and palliative care for advanced cancer patients**
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**The double life of double effect**
Theoretical Medicine and Bioethics 2004; 25(1): 61-74

**Abstract:** The U.S. Supreme Court's majority opinion in Vacco v. Quill assumes that the principle of double effect explains the permissibility of hastening death in the context of ordinary palliative care and in extraordinary cases in which painkilling drugs have failed to relieve especially intractable suffering and terminal sedation has been adopted as a last resort. The traditional doctrine of double effect, understood as providing a prohibition on instrumental harming as opposed to incidental harming or harming as a side effect, must be distinguished from other ways in which the claim that a result is not intended might be offered as part of a justification for it. Although double effect
might appropriately be invoked as a constraint on ordinary palliative care, it is not clear that it can be coherently extended to justify such practices as terminal sedation. A better approach would reconsider double effect's traditional prohibition on hastening death as a means to relieve suffering in the context of acute palliative care.

Boyle, Joseph

**Medical ethics and double effect: the case of terminal sedation**

Theoretical Medicine and Bioethics 2004; 25(1): 51-60

**Abstract:** The use of terminal sedation to control the intense discomfort of dying patients appears both to be an established practice in palliative care and to run counter to the moral and legal norm that forbids health care professionals from intentionally killing patients. This raises the worry that the requirements of established palliative care are incompatible with moral and legal opposition to euthanasia. This paper explains how the doctrine of double effect can be relied on to distinguish terminal sedation from euthanasia. The doctrine of double effect is rooted in Catholic moral casuistry, but its application in law and morality need not depend on the particular framework in which it was developed. The paper further explains how the moral weight of the distinction between intended harms and merely foreseen harms in the doctrine of double effect can be justified by appeal to a limitation on the human capacity to pursue good.

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