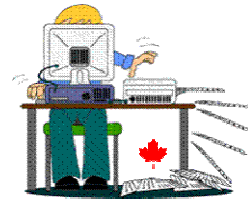


Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

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Compilation of Media Watch 2008, 2009, 2010, 2011 ©

Compiled & Annotated by Barry R. Ashpole

Care planning: Scroll down to [Specialist Publications](#) and 'Failing to plan is planning to fail: Advance care planning for people nearing the end of life' (p.7), published in *Aging Health*.

Canada

We are failing our seniors and our family caregivers

BRITISH COLUMBIA | *The Province* – 21 October 2011 – Canada's population is aging. Canadians are having fewer babies and are living longer. By 2031, a quarter of Canadians will be 65 years or older, double the proportion of seniors today. The proportion of Canada's oldest seniors, those over 80 years of age, is expected to triple in the next four decades, meaning one in 10 Canadians will be over 80 years of age. Not only are Canadians living longer, they are living longer with multiple chronic health conditions, placing increasing pressure on the health and social care systems, and on Canada's 1.5 to 2 million family caregivers. The increasing emphasis on health-care delivery in the home setting and in the community has meant the family caregiver continues to shoulder a greater burden of care. Although the health-care system continues to increase the burden on caregivers, we have failed to recognize that trend from a public policy perspective and to

put in place measures to ease the financial, emotional and psychosocial effects on caregivers. <http://www.theprovince.com/health/Essay+failing+seniors+family+caregivers/5491070/story.html>

Only 35% of households with caregivers report income over \$45,000. An overwhelming 77% of caregivers are women.

[Specialist Publications](#)

Of particular interest:

'Complexities in the provision of respite care to family carers of persons with intellectual disabilities' (p.8), published in *Disability, CBR & Inclusive Development*

N.B. A sidebar to this article lists links to several articles in *The Province* related to family caregivers.

Perceptions

Editorial wrong about hospice palliative care

BRITISH COLUMBIA | BC Local News (Letter) – 19 October 2011 – Your editorial¹ ... provided clear information on the very real challenges surrounding the delivery of quality end-of-life care and the need for more supports. What puzzled me was the sentence stating "not everyone wants to die at hospice where the staff is knowledgeable and compassionate, yet the atmosphere can seem like a hospital ward." In my experience, the care provided in the all too few residential hospice facilities and palliative care units located in communities and hospitals around B.C. is exceptional. In truth, there is no "right place to die." If it can be managed, most of us would probably opt to stay home. But when that's not possible, then hospice and palliative programs, whether they are residential or hospital based, are second to none in providing exactly the right level of care that respects the needs of the "whole" person (patient) and their family. Some of the surroundings are more home-like than others, but it truly doesn't get any better – the editorial was way off-base. <http://www.bclocalnews.com/opinion/letters/132200443.html>

1. 'End-of-life care needs attention,' BC Local News, 4 October 2011. http://www.bclocalnews.com/vancouver_island_central/nanaimonewsbulletin/opinion/131009973.html

U.S.A.

The promise and pitfalls of palliative care

CALIFORNIA | *Los Angeles Times* – 24 October 2011 – What if a new medication for severely ill patients had no role in curing them but made them feel much better despite being sick? Let's say this elixir were found to decrease the pain and nausea of cancer patients, improve the sleep and energy of heart failure patients, prolong the lives of people with kidney failure, drive down healthcare expenditures and ease the burdens of caregivers? Those are the promises of a fledgling medical specialty called palliative care – not a new drug but a new way of treating patients who are living, often for years, with acute or chronic illnesses that are life-threatening. If palliative care were a pill, government regulators would very likely approve it for the U.S. market. Federal healthcare insurance programs would quickly agree to pay physicians and hospitals for treating patients with the new therapy. And patients would make it a blockbuster drug in no time flat.

Yet uncertainties cloud the prospects for palliative care. Among the unanswered questions: Who will pay for these services, where will this new field's workforce come from, and what is it – cost savings or compassion – that drives this new branch of medicine? <http://www.latimes.com/health/la-he-palliative-care-20111024,0,4249424.story>

Extract from *Los Angeles Times* article

Providing comfort, emotional support and coordination of specialized care used to be the job of the family physician. But few families these days have a longstanding relationship with a single physician, and even fewer doctors have the expertise or time, while trying to cure a very ill patient, to coordinate his care and tend to his physical and psychological distress.

- CALIFORNIA | *Los Angeles Times* – 24 October 2011 – **'The costs of palliative care teams.'** Some of the most daunting challenges to the expansion of palliative care come down to payments and people. Despite early research suggesting there are eventual cost savings in palliative care, setting up a palliative care team does require an investment. And in a medical care system that largely rewards doctors and hospitals for performing procedures, many financially strapped hospitals ask whether and how palliative care teams will pay for themselves. <http://www.latimes.com/health/la-he-palliative-care-side-20111024,0,6155818.story>

End-of-life care: Extending life, or prolonging death?

FLORIDA | *Herald Tribune* (Sarasota) – 19 October 2011 – Medical advances most Americans see as life-extending are often death-prolonging, leading to difficult treatment decisions in times of crisis, said a panel of experts [at the University of South Florida Sarasota-Manatee]. "Unless you die suddenly" – which only happens 10% of the time said Richard Deibert, a medical doctor and theologian – "you and I will have the opportunity to choose a long and slow and twisting death." Panelists specializing in legal, social and spiritual aspects of death agreed that costly and largely futile medical care at the end of life often result from families' failure to discuss their wishes. The silence stems from "the dread of dying that has infested American life in the 21st century," Deibert said, describing it as a cultural dilemma expressed by a "no-wait obsession" in hospital emergency rooms and the idea of "our right to be free of suffering," which can overload intensive care units. <http://www.heraldtribune.com/article/20111019/ARTICLE/111019480>

Of related interest:

- *WASHINGTON POST* | Online article – 17 October 2011 – '**Accepting death is difficult for patients and doctors, but it needs to be done.**' We will all die, but the trajectory of our death will follow one of a few predictable patterns. According to statistics published in 2003¹ ... two-fifths of us will die with prolonged, dwindling illness on a slow downward slope typical of dementia or frailty. One-fifth will die with a sharp decline typical of, for example, metastatic cancer. Another fifth will die with intermittent dips, like a roller coaster, from heart or lung failure; and a small percent will die suddenly and unexpectedly, like falling off a cliff. Nearly 80% of us want to die at home, polls have shown, but most die in the hospital, often strapped to a bed in the intensive care unit. And a recent study² suggests that many people are subjected to surgery, even in the last week of their lives. http://www.washingtonpost.com/national/health-science/accepting-death-is-difficult-for-patients-and-doctors-but-it-needs-to-be-done/2011/07/13/gIQRq4AsL_story.html
 1. 'Patterns of functional decline at the end of life,' *Journal of the American Medical Association*, 2003;289(18):2387-2392. <http://jama.ama-assn.org/content/289/18/2387.full>
 2. 'The intensity and variation of surgical care at the end of life: A retrospective cohort study,' *The Lancet*, 2011;378(9800):1408-1413 (noted in Media Watch dated 10 October 2011). <http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2811%2961268-3/abstract>

Media Watch Online

The weekly report can be accessed at several websites, among them:

Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx>

Ontario | HPC Consultation Services: <http://www.hpconnection.ca/newsletter/inthenews.html>

Ontario | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1>

U.S.A.

Prison Terminal: <http://www.prisonterminal.com/news%20media%20watch.html>

International

Global | Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

International Palliative Care Resource Center: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/news.htm>

At end of life ... soaring prices, sinking resources

NATIONAL PUBLIC RADIO (NPR) | 'Tell Me More' (series) – 17 October 2011 – The price for aging and end of life care may be growing out of reach for many individuals and families. The average annual cost of a private room in a nursing home is more than \$80,000, while the average price for assisted living is close to \$40,000. All this when the average senior takes in around \$30,000 annually, including Social Security and pension benefits. The Obama administration had hoped one provision of its signature health care law would help alleviate some of that financial stress with a program to help pay for long term care, but ... the Community Living Assistance Services & Supports Program (CLASS) was declared financially unworkable by the head of the Department of Health & Human Services, Kathleen Sebelius. <http://www.npr.org/templates/story/story.php?storyId=141418428>

From Media Watch dated 17 October 2011:

- REUTERS | Online report – 14 October 2011 – **'U.S. suspends home-care program from healthcare law.'** U.S. health officials said they were suspending a program to provide home care for the elderly and disabled. The insurance program was passed as part of President Barack Obama's overhaul of the nation's healthcare system, but Republican opponents have said it was not financially sound. <http://www.trust.org/alertnet/news/us-suspends-home-care-program-from-healthcare-law/>

N.B. Links to each episode in the NPR series on end of life: <http://www.npr.org/series/141454355/the-end-of-life>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- HAWAII | United Press International – 17 October 2011 – **'1909 Hawaii law at center of death debate.'** Proponents and opponents of assisted suicide in Hawaii say they are locked in debate over a 102-year-old provision of state law that seems to allow it. Proponents are pushing to make Hawaii the fourth U.S. state to legalize physician-assisted death, ABC News reported Monday. http://www.upi.com/Health_News/2011/10/17/1909-Hawaii-law-at-center-of-death-debate/UPI-64641318907764/

Medicare eyes hospice for savings

POLITICO.COM | Online article – 17 October 2011 – Now, the hospice industry ... is facing two separate rounds of cuts. And some researchers and advocates worry about the repercussions. Hospice faces about \$7billion in Medicare payment reductions over a decade under the health care reform law. On top of that, the summer's debt reduction deal will trigger a 2% cut in 2013 – unless the deficit super-committee reaches its own agreement. Thirty years after its inclusion as a Medicare benefit, hospice is having a bit of a midlife crisis. Changes in whom it serves, where it serves them and for how long are affecting the bottom line, in ways that may accelerate trends that are already reshaping end-of-life care. <http://www.politico.com/news/stories/1011/66177.html>

Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>



International

'Many Britons unable to pay funeral cost'

U.K. | Press TV – 22 October 2011 – As the economic crisis gripping the British society compounds and the British government's commitment to its austerity drive remains "unwavering," the number of financially pressed British families who cannot afford to pay for the burial of their family members is on the rise. A research study conducted by the Local Government Association (LGA) revealed that the Public Health (Control of Disease) Act 1984 obliged councils in Britain to fund around 3,000 funerals across the country last year. The average cost of each funeral is around £950 causing the councils to incur a total cost of £2,110,000. Under the current law, British councils are responsible for the burial of those dying outside of a hospital when there is no one to pay for the costs involved. Local authorities who took part in the study criticized the government for its complex, "outdated" and "confusing" bureaucracy and red tape that prevent families from claiming grants. "The last thing a grieving relative needs is extra stress over whether they're going to be able to pay for and organize the funeral of their loved one," said David Rogers, chairman of the LGA's community wellbeing board. <http://www.presstv.ir/detail/205945.html>

Sharp increase in palliative care admissions

AUSTRALIA | ABC News – 19 October 2011 – The number of Australians being admitted to hospital for palliative care has increased by 56% in the past decade. A report by the [Australian] Institute of Health & Welfare¹ found patients who are in the last stages of life stay in hospital for about 12-and-a-half days, which is almost four times longer than the average hospital admission. The Institute's Brent Diverty says there were more than 50,000 palliative care admissions to Australian hospitals in 2008-2009. "We looked over the past 10 years at trends in palliative care in hospitals and we are seeing a significant increase," he said. "What the figures show is that over a 10-year period from 1999 to 2009, the number of palliative care admissions rose by 56%. About half of palliative care admissions are 75 years plus. But interestingly enough, 12% are under 55 years of age." <http://www.abc.net.au/news/2011-10-19/palliative-care/3578230>

1. *Trends in palliative care in Australian hospitals*, Australian Institute of Health & Welfare, October 2011. <http://www.aihw.gov.au/publication-detail/?id=10737420167>

N.B. Australia rated 2nd in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Facing death without fear

IRELAND | *Irish Times* – 18 October 2011 – Palliative medicine consultant Dr. Dymphna Waldron [of Galway University Hospital] says that despite the despair of an advanced illness such as cancer, there is an adaptation that can occur in a person which allows an improved quality of life as they near death once the significant relationships in their life have been dealt with. "The philosophy of our palliative care service is that by helping patients to live both pain and symptom-free and with good subjective quality of life, we empower them to live as whole and independent a life as possible, maintaining and enhancing rich relationships. By living well with maximum support, our experience is that patients die with peace of mind surrounded with serenity and dignity," she says. <http://www.irishtimes.com/newspaper/health/2011/1018/1224305986607.html>

From Media Watch dated 17 October 2011:

- IRELAND | *Irish Central* – 13 October 2011 – **'Irish Prime Minister urges people to prepare for death.'** Irish Prime Minister Enda Kenny has urged people to prepare for their death – and discuss it with family and friends. The Fine Gael leader made the remarks at the Dublin Forum on End of Life conference in the capital. <http://www.irishcentral.com/news/Irish-Prime-Minister-urges-people-to-prepare-for-death---131778833.html>

New hospice needed to cope with health cuts in south Essex

U.K. | *Echo* (Essex) – 18 October 2011 – A new hospice is needed in Southend to relieve the strain likely to be caused by impending health cuts. Havens Hospices ... says local primary care trusts are being forced to cut £300 million from their budgets over the next four years, forcing more people to seek help from hospices. NHS [National Health Service] South East Essex and NHS South West Essex have both said they plan to send fewer people with long-term, terminal conditions to hospitals. Such a decision would put extra pressure on Havens, which turned away 49 people ...from its adult hospice last year because it had no beds for them. http://www.echo-news.co.uk/news/9311090.New_hospice_needed_to_cope_with_health_cuts_in_south_Essex/

Has TV gone too far this time? Body of terminally ill man is mummified for Channel 4 documentary

U.K. | *Daily Mail* (OpEd) – 17 October 2011 – A man who died from a terminal illness has been mummified like an Egyptian pharaoh for a Channel 4 show. The broadcaster looks set to find itself at the centre of another taste row after agreeing to air the macabre documentary. Sources say the dead man ... had a keen interest in preservation techniques used at the time of Tutankhamun. The programme will make television history when it airs on Monday, 24 October, as a scientific embalming experiment is unprecedented. <http://www.dailymail.co.uk/news/article-2049740/Body-terminally-ill-man-mummified-Channel-4-documentary.html>

From Media Watch dated 11 January 2010:

- U.K. | *Daily Mail* – 11 January 2010 – '**Channel 4 seeks terminally ill volunteer to be mummified in TV documentary.**' If the project goes ahead it will follow a trail of programmes which seek to challenge views on death. Television audiences have been shown an autopsy ...and an on-screen suicide. <http://www.dailymail.co.uk/sciencetech/article-1242225/Channel-4-advertising-terminally-ill-person-volunteer-mummified-TV-show.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | Press Association – 20 October 2011 – '**Royal College of Nursing gives guide on assisted suicide.**' Nurses have been given new guidelines on how to respond to questions from patients in relation to assisted suicide. The document¹ ... warns nurses and health care assistants that assisting a suicide and offering information on euthanasia is illegal. But it gives advice on how to deal with "difficult conversations" with patients, and tells nurses not to "raise the issue of assisted suicide."<http://www.google.com/hostednews/ukpress/article/ALeqM5jZ8FLbLgRIV0V1tEJiXbKmlp8iA?docId=N0178671319099891587A>
 1. *When someone asks for your assistance to die*, Royal College of Nursing, 2011. http://www.rcn.org.uk/_data/assets/pdf_file/0004/410638/004167.pdf
- U.K. | *Daily Mail* – 20 October 2011 – '**Don't mention Dignitas: Nurses warned they could be jailed for talking about assisted suicide.**' Nurses will be told they could go to prison for talking to patients about assisted dying. They will be warned they face prosecution if they are found to have discussed any aspect of euthanasia with a patient who goes on to commit suicide. The new Royal College of Nursing guidelines will remind staff that it is illegal to offer information about assisted dying ... in case it is seen as 'encouragement.' <http://www.dailymail.co.uk/health/article-2051179/Dignitas-Nurses-warned-jailed-talking-assisted-suicide.html?ito=feeds-newsxml>
- U.K. (Isle of Man) | *isleofman.com* – 17 October 2011 – '**Island advocate highlights "tax pitfall" over assisted suicide.**' An advocate has pinpointed ... a "financial pitfall" for offshore tax residents who may be thinking about assisted suicide. Relocation to Switzerland for an assisted suicide could lead to an unforeseen tax bill. Last year 694 people from the U.K. travelled to the Dignitas clinic in Zurich to end their lives. <http://www.isleofman.com/News/article.aspx?article=40169>

Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

Failing to plan is planning to fail: Advance care planning for people nearing the end of life

AGING HEALTH, 2011;7(5):677-680.

Following the inaugural meeting in Melbourne, Australia, in 2010, the newly formed International Society for Advance Care Planning & End of Life Care held its second International 3-day conference in London in June this year. This article gives an overview of the conference and one delegate's perspective. With over 400 delegates from across the world representing 22 different countries, the conference and society represent the increasing international recognition of the importance of holding and recording advance care planning discussions with people nearing the end of their lives, with a particular focus on the growing needs of the elderly in our society.

<http://www.futuremedicine.com/doi/pdf/10.2217/ahe.11.67>

Of related interest:

- *EMERGENCY MEDICINE JOURNAL* | Online article – 19 October 2011 – **'Emergency clinicians' attitudes and decisions in patient scenarios involving advance directives.'** Hypothetical treatment decisions involving advance directives made by emergency clinicians appear to be more influenced by ethical and clinical factors than by legal obligations [based on the findings of an online survey]. <http://emj.bmj.com/content/early/2011/10/18/emered-2011-200287.abstract>
- *RESPIROLOGY* | Online article – 18 October 2011 – **'Advance care planning in chronic obstructive pulmonary disease (COPD).'** Advance care planning (ACP) can improve outcomes for patients and their relatives. The challenge remains in the practical implementation of ACP in the clinical setting, especially for patients with COPD. <http://onlinelibrary.wiley.com/doi/10.1111/j.1440-1843.2011.02087.x/abstract>

GPs urged to find the 1% of patients with a year to live

GP (U.K.) | Online article – 24 October 2011 – Around 1% of the population dies each year and the 'Find Your 1%' campaign aims to get GPs talking to patients likely to die within the year 'as early as possible' about wishes for palliative care. But Northumberland LMC [Local Medical Committee] secretary Dr. Jane Lothian, who is involved with local palliative care work, questioned the ethics of the 'somewhat arbitrary' selection of patients. The Dying Matters Coalition campaign is part of the government's Quality, Innovation, Productivity & Prevention (QIPP) agenda.¹ It seeks to persuade GPs to discuss end-of-life care with patients who are likely to die in the next 6-12 months, in order to increase the number of people dying in their usual place of residence. Dr. Lothian agreed that GPs should be 'proactive' about discussing palliative care. 'It's a skill of any primary care doctor, practice or district nurse,' she said. 'Usually it's about allowing people space to have that discussion.' But she said patients often feel 'duty-bound' to simply follow the doctor's lead without knowing they have choices, such as where they would like to die. She added that it would be 'extremely difficult' for GPs to predict who was going to die in the coming year, other than those already dying. 'Picking out people in a somewhat arbitrary way is very difficult.' <http://www.gponline.com/News/article/1100086/gps-urged-find-1-patients-year-live/>

1. 'Find Your 1% QIPP Campaign: <http://www.dyingmatters.org/gp>

Chemotherapy versus supportive care alone in pediatric palliative care for cancer: Comparing the preferences of parents and health care professionals

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 17 October 2011 – Important factors influencing the decision between therapeutic options were child quality-of-life and survival time among both parents and health care professionals. Compared with health care professionals, parents more strongly favour aggressive treatment in the palliative phase and rank hope as a more important factor for making decisions about treatment. Understanding the differences between parents and health care professionals in the relative desirability of supportive care alone may aid in communication and improve end-of-life care for children with cancer. <http://www.cmaj.ca/content/early/2011/10/17/cmaj.110392>

Of related interest:

- *JOURNAL OF HOSPITAL MEDICINE* | Online article – 12 October 2011 – '**Pediatric hospital medicine: A strategic planning roundtable to chart the future.**' Given the growing field of pediatric hospital medicine and the need to define strategic direction, the Society of Hospital Medicine, the American Academy of Pediatrics, and the Academic Pediatric Association ... discuss the future of the field. <http://onlinelibrary.wiley.com/doi/10.1002/jhm.950/full>

Integration of palliative medicine into routine oncological care: What does the evidence show us?

JOURNAL OF ONCOLOGY PRACTICE, 2011;7(6):1-5. Medical oncologists have routinely provided palliative care to patients along with antineoplastic therapy. Nevertheless, there is a recognized need for an improvement in palliative care delivery to the patient with advanced cancer. This narrative review outlines recent clinical trials of palliative care being integrated into routine oncological care. <http://www.jop.ascopubs.org/site/er/JOP000351.pdf>

Complexities in the provision of respite care to family carers of persons with intellectual disabilities

DISABILITY, CBR & INCLUSIVE DEVELOPMENT, 2011;22(2):38-54. Three main themes dominated the discussions [i.e., focus groups]. The first theme related to the ambivalence of carers towards using respite services, as expressed in their reluctance to relinquish care-giving for even a short period; the feelings of guilt they experienced; and the greater needs of other carers. The second theme related to the benefits of respite breaks, but these were solely with respect to the carer and other family members, rather than to the person with an intellectual disability. The third theme regarding the quality of provision was dominated by concerns for the care the person received in using the services. <http://dcidj.org/article/view/22>

End-of-life decisions in cases of vegetative state from the legal point of view

FORTSCHRITTE DER NEUROLOGIE – PSYCHIATRIE, 2011;79(10):582-587. The perspective of having to "vegetate" in a so-called persistent vegetative state over an indefinite period of time is regarded as unacceptable by many people. How to operationalise and enforce the patients "right of self-determination" in such cases is a subject of current medical and ethical debate. In addition, there is great uncertainty about how far and how long further treatment or supply is still indicated in such cases. The article discusses the legal framework and illustrates existing uncertainties and points out those aspects that demand clarification. <https://www.thieme-connect.de/ejournals/abstract/fdn/doi/10.1055/s-0031-1281741>

N.B. Article in German.

Systematic review of the primary research on minority ethnic groups and end-of-life care from the U.K.

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 17 October 2011 – The results highlight the multiple and related factors that contribute to low service use and sub-standard quality of services experienced by minority ethnic groups, and the need for authors to clarify what they mean by "culturally competent" end-of-life care. The synthesis of diverse and disparate studies underpins a number of key recommendations for health care professionals and policymakers. Tackling these epidemiological, demographic, institutional, social, and cultural factors will require a systematic and organization-wide approach rather than the current piecemeal and reactive interventions. [http://www.jpsmjournal.com/article/S0885-3924\(11\)00375-7/abstract](http://www.jpsmjournal.com/article/S0885-3924(11)00375-7/abstract)

Of related interest:

- *MEDICAL CARE*, 2011;49(11):992-998. **'Racial disparities in in-hospital death and hospice use among nursing home residents at the end of life.'** Differential use of feeding tubes, do-not-resuscitate and do-not-hospitalize orders lead to racial differences in in-hospital death and hospice use. Remaining disparities are primarily due to overall end-of-life care practices in predominately black facilities... http://journals.lww.com/lww-medicalcare/Abstract/2011/11000/Racial_Disparities_in_In_hospital_Death_and.6.aspx

Report finds improvements in nursing home care

NURSE.COM (U.S.) | Online report – 17 October 2011 – A new report¹ shows that America's nursing facilities have continued to build on quality improvements reported in previous years and have achieved measurable improvements in nine out of 10 quality measures since 2009. <http://news.nurse.com/article/20111017/NATIONAL02/110170036/-1/frontpage>

1. 2011 Annual Quality Report, Alliance for Quality Nursing Home Care and the American Health Care Association: <http://agnhc.org/2011qualityreport/>

What is the role of specialist palliative care in an acute hospital setting? A qualitative study exploring views of patients and carers

PALLIATIVE MEDICINE | Online article – 17 October 2011 – All patients ... were treated in an acute hospital, described as a bewildering and pressured environment of care. Initial perceptions of palliative care were varied, some interpreting referral as an indication that they were approaching the end of life. However, after palliative care input, patients and carers developed an understanding of their role, which they saw as three-fold: physical symptom control; psychological support; and, a reliable liaison. The theme of cross-cutting interviews was that the palliative care team made time for patients, giving them a sense of value and worth. Feeling their care was a priority and being listened to made palliative care input effective. Findings will aid continuing development and evaluation of palliative care teams, in the domains of effectiveness as well as patient experience. <http://pmj.sagepub.com/content/early/2011/10/13/0269216311425097.abstract>

From Media Watch dated 15 August 2011

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online article – 9 August 2011 – **'Exploring health professionals' views regarding the optimum physical environment for palliative and end of life care in the acute hospital setting: A qualitative study.'** Many deficiencies exist in physical hospital environments for patients at the end of life. However, changes to the hospital environment are limited by resource restrictions, increasing rules and regulations, and a focus on clinical aspects of care. <http://spcare.bmj.com/content/early/2011/08/09/bmjspcare-2011-000045.abstract>

Patient self-reporting in palliative care using information technology: Yes, there is hope!

PALLIATIVE MEDICINE, 2011;25(7):673-674. Patient self-report is especially critical in palliative care, particularly as palliative care moves earlier into the illness trajectory when patients are more functional and able to self-report. Palliative care inherently prioritizes patient-reported information such as symptoms, quality of life, and physical function. Patient-reported concerns (e.g., pain or breathlessness) are often severe and warrant attention, are subject to frequent or precipitous change, and are often poorly rated by proxies. Increasingly, other disciplines, like oncology and pain medicine, are incorporating electronic patient-reported outcomes systems into routine practice. <http://pmj.sagepub.com/content/25/7/673.full>

White Paper on Standards and Norms for Hospice and Palliative Care in Europe: Part 1

ZEITSCHRIFT FÜR PALLIATIVMEDIZIN, 2011;12(5):216-227. The focus of this White Paper is on norms and standards for hospice and palliative care in Europe as recommended by the EAPC [European Association for Palliative Care]. In addition to the structure of care, many other dimensions play an important role in the provision of quality hospice and palliative care – such as treatment methods, quality and outcome measurement, research, education, funding, policy and organisation, and legislation. The White Paper presents a common terminology and standards that have been formulated in a consensus procedure with the European palliative care associations. <http://cat.inist.fr/?aModele=afficheN&cpsid=24467385>

N.B. Article in German.

Worth Repeating

A request for nondisclosure: Don't tell mother

JOURNAL OF CLINICAL ONCOLOGY, 2007;25(31):5030-5034. Mrs. X was a 75-year-old woman who was admitted to the hospital with abdominal pain and severe depression. Her work-up revealed metastatic pancreatic cancer. Given her functional and nutritional status, her prognosis was less than 3 months. The patient had two daughters who were adamant that no one should tell their mom she has cancer. They understood that treatment was unlikely to prolong her life and wanted to take her home with hospice. You are unsure what to do – you feel like the patient has a right to know and yet her family is adamant that you cannot tell her because it will "kill her." Requests for nondisclosure, as reflected in the case, may cause clinicians considerable distress. Does not the patient have a right to know the truth? What about informed consent and patient autonomy? Am I being asked to hide the truth or lie? Although the topic of nondisclosure raises legitimate ethical questions, we believe these cases are too often conceptualized as dilemmas in which one party must win and the other must lose: either the family is overridden and the patient told her diagnosis, or the physician's conscience is violated and the patient is not told. A large literature lays out the arguments for and against disclosure in these cases. We think, however, there is a third way that often allows satisfaction of the patient, the family, and the physician's concerns. This method depends on an understanding of the cultural factors that underlie the family and physician's views and skilful use of negotiation techniques. In this article, we briefly review the literature on nondisclosure and provide some suggestions for handling requests similar to that posed in the case. <http://jco.ascopubs.org/content/25/31/5030.full>

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

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Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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