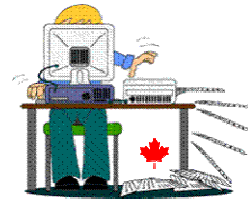


Media Watch...

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

Towards agreed-on clinical outcomes: Scroll down to **Specialist Publications** and 'Time-limited trials near the end of life' (p.0), published in the *Journal of the American Medical Association*.

Canada

Wait for long-term care now four years

ONTARIO | *Ottawa Citizen* – 8 October 2011 – Arnprior needs more nursing-home beds to cut a waiting list that has stretched to four years, making it one of eastern Ontario's overlooked and under-served areas for elder care, says the chief executive of the Arnprior & District Hospital. Eric Hanna is pleading for more provincially funded nursing-home beds as eastern Ontario hospitals try to prevent a growing number of elderly patients from being admitted prematurely to long-term care. Instead of automatically labelling them candidates for nursing homes, some hospitals ... have started to emphasize the importance of keeping older patients mobile,

or helping them regain as much of their function as possible. The goal is to maximize the chance of discharging seniors home, even if it means enhanced home-care services. http://www.ottawacitizen.com/health/Wait+long+term+care+four+years/5524163/story.html?cid=megadrop_story

Extract from *Ottawa Citizen* article:

The hospital's own analysis of its elderly patients has found that nearly two-thirds of them could benefit from discharge to home with enhanced support services, or the rehab-to-home approach.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | Canadian Press – 6 October 2011 – '**Doctors and patients call for death with dignity in B.C. Supreme Court documents.**' A woman who watched her husband die a gruesome death, only to discover she too had lung cancer is one of several patients and physicians asking the court to strike down Canada's assisted-suicide laws. Susan Bracken of Barrie, Ontario, filed an affidavit with the B.C. Supreme Court, saying she strongly believes that a person should have the right to choose to die. <http://www.winnipegfreepress.com/canada/breakingnews/doctors-and-patients-call-for-death-with-dignity-in-bc-supreme-court-documents-131292239.html>

U.S.A.

End-of-life care ... for profit

CALIFORNIA | *Sacramento Business Journal* – 7 October 2011 – Hospice care, which began as a grassroots movement run by volunteers, has become a multibillion-dollar business. Rapid growth by for-profit companies that dominate the national market has heightened competition and increased options for care – but also has raised questions for some about whether it's appropriate for a commercial enterprise to make money off of the most vulnerable of patients. The number of for-profit hospices in the U.S. grew 142% from 2000 to 2009, while the number of nonprofits declined by 1%. For-profit providers now account for 53% of the market. Their average profit margins were 10% in 2008, the last data available. The average margin for nonprofits was 0.2%. Although patients of all ages qualify and use hospice services, well over two-thirds of the more than 1.6 million patients who receive hospice services annually are seniors covered by Medicare. <http://www.bizjournals.com/sacramento/print-edition/2011/10/07/first-health-care-story.html>

From Media Watch dated 12 September 2011:

- *THE HOSPITALIST* (U.S.) | Online report – 7 September 2011 – '**Hospitalists see value in palliative care.**' Hospital medicine groups looking for a new revenue stream would be well served to keep an eye on the explosive growth of palliative care, according to a former Society for Hospital Medicine president who also runs a palliative care service. http://www.the-hospitalist.org/details/article/1338921/Hospitalists_See_Value_in_Palliative_Care.html

N.B. Several articles on trends in for-profit hospices in the U.S. are noted in Media Watch dated 8 August 2011 (p.11) and 1 August 2011 (p.5).

Death sentence: Appleton native's work with a prison hospice leads to book on finding dignity in dying

WISCONSIN | *Post-Crescent* (Appleton) – 7 October 2011 – For many inmates sentenced to life in prison, life will end living among other hardened criminals, locked away from a world they wronged. They will die behind bars. How they die matters to Lori Waselchuk. The Appleton native and photographer, now 47, was privy in 2006 to a more compassionate side of prison life when asked by *Imagine Louisiana* to produce a photo essay on the hospice program at Louisiana State Penitentiary. Waselchuk ... continued documenting the programchronicled in her *Grace Before Dying*. <http://www.postcrescent.com/article/20111009/APC04/111007059/Death-sentence-Appleton-native-s-work-prison-hospice-leads-book-finding-dignity-dying>

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of (p.0).

Does profit motive explain high rates of end-of-life surgery?

CBS News | Online report – 7 October 2011 – New research shows that many elderly patients get surgery at the end of life¹ – and some are saying the operations are being performed not because the patients want or need them, but because the surgeons and hospitals are financially motivated to do surgery. Researchers analyzed data from nearly 2 million Medicare patients, aged 65 and older, all of whom who died in 2008. The researchers found nearly one in five of them underwent surgery in their last month of life, with one out of 10 undergoing a procedure in the week before they died. The study suggests many of these patients were already going to die. http://www.cbsnews.com/8301-504763_162-20117373-10391704.html

1. 'The intensity and variation of surgical care at the end of life: A retrospective cohort study,' *The Lancet*, published online 6 October 2011. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)61268-3/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61268-3/abstract)

Downsides of cancer care rarely seen in black media

REUTERS | Online report – 5 October 2011 – Few media stories on cancer venture into issues of death, dying and end-of-life care – and outlets directed at African Americans are particularly unlikely to do so, a new study suggests.¹ Historically, African Americans with advanced cancer have been more likely than whites to opt for aggressive treatment, and less likely to want hospice care. There's also evidence that hospice care, which is usually provided at home, does not speed death – and in some cases, may help people live longer than aggressive cancer treatment would. But doctors often don't bring up options for end-of-life care – even those caring for people with advanced cancer. <http://www.reuters.com/article/2011/10/05/us-downsides-cancer-care-idUSTRE79455V20111005>

1. 'Is public communication about end-of-life care helping to inform all? Cancer news coverage in African American versus mainstream media,' *Cancer*, published online 22 September 2011 (noted in Media Watch dated 3 October 2011). <http://onlinelibrary.wiley.com/doi/10.1002/cncr.26499/full>

State-by-state report card

State gets B for palliative care services

NEW JERSEY | *Herald News* – 4 October 2011 – Four in five New Jersey hospitals have palliative care programs to help the sickest patients, earning the state a B grade in a national report card issued by a health care advocacy group.¹ New Jersey's grade should improve in the next [state-by-state] survey as hospitals work to move patients away from the high-use end-of-life intensive care to more desirable alternatives, said Kerry McKean Kelly ... [of the] ... New Jersey Hospital Association. The state's "health care community has been keenly focused on this issue for several years, especially after national data showed that New Jersey has more intensive levels of medical interventions in the last six months of life than other parts of the country," she said. Overall, the nation got a B, up from a C as more programs have emerged, according to the report. http://www.northjersey.com/news/health/131121413_State_gets_B_for_palliative_care_services.html

Hospice a victim of lengthier medical treatments

CONNECTICUT | *Stamford Advocate* – 5 October 2011 – Shorter patient stays due to a trend among doctors to opt for lengthier treatments before considering end-of-life care is being blamed for the planned closure of the Richard L. Rosenthal Hospice Residence. Mark Santagata, of the Visiting Nurse & Hospice Care of Southwestern Connecticut, which owns and operates the home, said over the past three years, the average patient stay at the center fell from 22.1 days to 9.6 days. The decline in the number of days patients are staying combined with an unresolved proposal to simplify the state's hospice regulations to make them eligible for Medicare reimbursements for treatment costs resulted in the Visiting Nurse board to seek state approval to close the facility. The facility, which opened in June 2000, has cared for more than 1,000 dying residents on a 24-hour-basis. <http://www.stamfordadvocate.com/news/article/Hospice-a-victim-of-lengthier-medical-treatments-2204942.php>

1. 'America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care,' Center to Advance Palliative Care, October 2011. <http://www.capc.org/reportcard/pdf/state-by-state-report-card.pdf>
- OREGON | *Portland Business Journal* – 5 October 2011 – '**Oregon hospitals rank high for palliative care.**' The percentage of Oregon hospitals that provide palliative care to seriously ill patients is high enough to garner the state an A grade from the Center to Advance Palliative Care. <http://www.bizjournals.com/portland/blog/2011/10/oregon-hospitals-rank-high-for.html>
 - UTAH | *The Salt Lake Tribune* – 5 October 2011 – '**Utah's 'comfort care' gets a C from palliative care advocates.**' Access to palliative care for ... Utahns lags behind most of the nation, despite many studies that show patients who receive comfort care even when they are near death live better and longer, a new state-by-state analysis says. <http://www.sltrib.com/sltrib/money/52676183-79/care-palliative-hospitals-patients.html.csp>

Advance directives might curb cost of end-of-life care

U.S. TODAY & WORLD NEWS | Online report – 4 October 2011 – Depending on where you live, having an advance directive may raise the odds that you'll receive hospice services and reduce the overall cost of your end-of-life care, a new study indicates.¹ "The most important finding from our study is the evidence that advance directives can be very important in shaping the care that's provided to patients," said study author Lauren Hersch Nicholas, a health economist at the Institute for Social Research at the University of Michigan. End-of-life care is often a controversial subject, and when policymakers are looking for ways to control Medicare costs, such care typically comes up in the discussion. That's not surprising, because end-of-life care accounted for more than one-quarter of Medicare spending last year, according to

background information in the study. One concern is that this spending may be largely earmarked for aggressive care that's not necessarily what the patient might have wanted. <http://health.usnews.com/health-news/managing-your-healthcare/articles/2011/10/04/advance-directives-might-curb-cost-of-end-of-life-care>

Specialist Publications

Of particular interest:

'The evolution of advance directives' (p.0), an editorial published in the *Journal of the American Medical Association*.

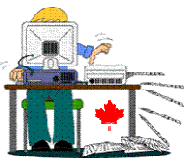
1. 'Regional variation in the association between advance directives and end-of-life Medicare expenditures,' *Journal of the American Medical Association*, 2011;306(13):1447-1453. <http://jama.ama-assn.org/content/306/13/1447.abstract>

Funding home care

Senate finds home healthcare companies at fault

WASHINGTON DC | Reuters – 3 October 2011 – The Senate Finance Committee said ... the biggest players in the home healthcare industry ... altered the course of patient care treatment to receive more reimbursements.¹ However, analysts suggested the conclusion of the investigation should help the Centers for Medicare & Medicaid Services better frame the final structure of reimbursement for home healthcare providers, which provide home-based nursing for the elderly with chronic diseases. Last year, the Securities & Exchange Commission, the Justice Department, and the Senate committee, launched investigations into home healthcare billing practices, prompted by a media report that suggested providers intentionally increased therapy visits to trigger higher reimbursements. <http://www.reuters.com/article/2011/10/03/us-home-healthcare-idUSTRE79268220111003>

1. 'Staff report on home health and the Medicare therapy threshold,' Senate Committee on Finance, September 2011. http://finance.senate.gov/imo/media/doc/Home_Health_Report_Final.pdf



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

World Hospice & Palliative Care Day: Sample news media coverage



INDIA | IBN Live (Bangalore) – 9 October 2011 – **'Awareness camp on palliative care.'** Kidwai Memorial Institute of Oncology is organising awareness camps across four colleges in the city. The Institute is focussing on youth to serve as volunteers to help end-stage cancer patients, especially the elderly, who need palliative care. <http://ibnlive.in.com/news/awareness-camp-on-palliative-care/191083-60-119.html>

INDIA | IBN Live (Chennai) – 9 October 2011 – **'Integrate palliative care with cancer treatment.'** A number of events organized across the city to mark World [Hospice &] Palliative Care Day stressed the need for integrating palliative care with cancer treatment so that the patients could be saved from both the physical and mental trauma caused by pain which accompanies the disease. <http://ibnlive.in.com/news/integrate-palliative-care-with-cancer-treatment/191338-60-120.html>

TAIWAN | *Taipei Times* – 8 October 2011 – **'Group promotes hospice care.'** A local hospice organization urged the public ... to sign consent forms indicating their willingness to use hospice care services in times of need. Not only would this allow terminally ill patients to express how they want to live, but it would also save family members the difficulty of making decisions for their loved ones when the time comes, the Taiwan Hospice Organization said. <http://www.taipeitimes.com/News/taiwan/archives/2011/10/08/2003515226>

U.K. | Press Association – 8 October 2011 – **'"Slow progress" on palliative care.'** Almost half of the world's countries have no provision for palliative care, according to new research.¹ The Worldwide Palliative Care Alliance study found 98 of the world's 234 countries (42%) do not have a hospice or palliative care services available to seriously-ill people and their families and carers. David Clark, from the School of Interdisciplinary Studies at the University of Glasgow, one of the report's co-authors, said: "We are encouraged that there has been a marked increase in the number of services in operation, from 10,000 in 2006 to 16,000 in 2011. <http://www.google.com/hostednews/ukpress/article/ALeqM5hCRxIIJXZTgP5NPCTqkJ6C0Tk38w?docId=N0823071318000768608A>

1. *Mapping level of palliative care development: A global update*, Worldwide Palliative care Alliance, 2011. <http://www.thewpca.org/latest-news/mapping-report-2011/>

UNITED ARAB EMIRATES (UAE) | Ameinfo.com – 6 October 2011 – **'Homecare specialist speaks out on World Hospice & Palliative Care Day.'** UAE patients requiring the relief of symptoms for chronic, non-contagious illnesses should be looked after in their own homes by palliative care professionals rather than remain in acute hospital settings, says a Dubai-based expert in community medicine. <http://www.ameinfo.com/277148.html>

Poll: Most Czechs wish to die at home, few do so

CZECH REPUBLIC | *Prague Daily Monitor* – 5 October 2011 – Some 78% of Czech would like to die at home, but very few do so, according to ... the polling institute STEM/MARK. Some 88% are ready to look after their family members and the same proportion consider home the best environment to die. About 69% of Czechs would like to have their family around them at the end of their lives and 45% their partner, while only 5% want to see medical personnel around them at this moment, the poll found. The analysts said the existing law did not make it possible to pay for the "mobile palliative care" with a doctor in the team. Thanks to this, most patients would not have to be in a hospital. "The support to family when looking after a dying family member by the state is very low as there is no day off for this purpose or a flexible system of financial help," the pollsters said. Czechs mostly die in long-term care facilities, pensioners' homes, hospitals and similar facilities. <http://praguemonitor.com/2011/10/05/poll-most-czechs-wish-die-home-few-do-so>

N.B. The Czech Republic was rated 21st 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

Taking skills beyond the hospice

U.K. | *Yorkshire Evening Post* – 5 October 2011 – Hospices may be associated with dying, but doctors from one Leeds facility are sharing their expertise with other patients in the city, and not always at the end of their lives. For patients with chronic kidney disease, a gruelling regime of dialysis three times a week was once the only treatment option. But thanks to an innovative approach being used in Leeds, those for whom the drawbacks may outweigh the benefits have another option. They can choose to have their condition managed without going onto lifelong dialysis, giving them a better quality of life in the time they have left. The project was started by Dr. Lynne Russon, who sees patients at St James's Hospital and works alongside medics specialising in kidney disease. http://www.yorkshireeveningpost.co.uk/news/news-features/consumer/health_taking_skills_beyond_the_hospice_1_3837352

Funding hospice

Health Lottery 'will be bad for hospice'

U.K. (WALES) | *South Wales Argus* – 4 October 2011 – St. David's Foundation is urging residents to shun the new national Health Lottery [an independent lottery game to raise funds for 'health-related good causes'] in fear that it could deprive local patients of the vital care services they need. The charity ... says it is reliant on the £500,000 generated each year by its own weekly fundraising lottery. It therefore fears that if people turn to the new Health Lottery ... then it will lose some of its vital funds. The Health Lottery will donate 20pence from every £1 spent to help local causes. But chief executive of St David's Foundation, Emma Saysell said that this amount is only just above the minimum amount required by

law and that due to the Health Lottery being a national initiative, players cannot be sure exactly who they will be supporting with the money. http://www.southwalesargus.co.uk/news/9284916.Health_Lottery_will_be_bad_for_hospice/

Specialist Publications

Of particular interest:

'[Health secretary Andrew] Lansley brings forward deadline for new palliative care funding regime' (p.0), published in *Nursing Times*.

Media Watch Online

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>

New Link

Surely the true cost of a cancer drug is the quality of life it gives the patient

U.K. | *Daily Telegraph* (OpEd) – 3 October 2011 – It seems that every few months we read about another wonder drug that the National Institute for Health & Clinical Excellence (NICE), the government organisation responsible for evaluating clinical treatments, has refused to fund on the NHS [National Health Service]. Is it right to put a price on someone's life? To decide what is cost-effective and what is not? Last week *The Lancet* published an article attempting to address just this¹ ... and was written by more than 30 world-renowned cancer specialists from Europe, the U.S. and Australia. In it, they concluded that many of the most costly drugs used in treating advanced cancer brought little value and argued that, with an ageing population, difficult decisions had to be made. <http://www.telegraph.co.uk/health/8799431/Surely-the-true-cost-of-a-cancer-drug-is-the-quality-of-life-it-gives-the-patient.html>

1. 'Delivering affordable cancer care in high-income countries,' *The Lancet Oncology*, 2011;12(10): 933-980. [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(11\)70141-3/abstract](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(11)70141-3/abstract)

From Media Watch dated 3 October 2011:

- U.K. | *Daily Telegraph* – 26 September 2011 – **'Dying cancer patients should not be given 'futile' drugs.'** A panel of leading academics said that the cost of treating cancer to western societies is spiralling out of control. <http://www.telegraph.co.uk/health/healthnews/8790468/Dying-cancer-patients-should-not-be-given-futile-drugs.html>

From Media Watch dated 17 January 2011:

- *HASTINGS CENTER REPORT*, 2011;41(1). **'The real-life death panel, reformed.'** The National Institute of Health & Clinical Effectiveness is one of the few public institutions in the world engaged in above-board, cost-based, health care priority-setting. Rightly or wrongly, it was making the tough calls, out in the open. <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5075>

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

On the journey with the dying: How general practitioners experience the death of their patients

DEATH STUDIES | Online article – 28 September 2011 – The participants [in this grounded theory study] explained their experience of a patient's death using the "death journey" metaphor. This journey ... could be described from five different moments in the participants' encounters with people who are dying: private acknowledgement, communication of prognosis, continuity of care, the moment of death, and looking after the family. The experience of death described by the GPs in this study was different from that reported by medical doctors in other care settings. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2011.553315>

Supporting hospice volunteers and caregivers through community-based participatory research

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online article – 6 October 2011 – This article addresses the need to enhance social support for caregivers of people with life-threatening illnesses. The findings [of this study] revealed communication, emotional support, education, advocacy and personal fatigue as the most important challenges to be addressed through support interventions at the organisational (professional support, volunteer mentoring and continuing education) and household levels (caregiver assessments, telephone support and follow-up). There was convergence in how caregivers perceived and access existing social supports, yet a crucial divergence in the availability of resources among volunteers and family members. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2011.01030.x/abstract>

Cont.

Of related interest:

- *INTERNATIONAL JOURNAL OF MEDICAL INFORMATICS* | Online article – 28 September 2011 – **'Theorizing the health service usage behavior of family caregivers: A qualitative study of an Internet-based intervention.'** This quantitative study found that less competent caregivers with more positive attitudes towards technology tended to use the intervention more frequently. <http://www.sciencedirect.com/science/article/pii/S1386505611001742>

Towards agreed-on clinical outcomes

Time-limited trials near the end of life

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2011;306(13):1483-1484. Clinicians, patients, and families frequently face scenarios in which they must make decisions near the end of life about whether to initiate major interventions in circumstances in which the outcome is uncertain. They do not want to prematurely forgo treatments that might help, but they also may not want to risk indefinite exposure to burdensome treatments. The possibility of a time-limited trial (TLT) of treatment may provide a way forward. A TLT is an agreement between clinicians and a patient/family to use certain medical therapies over a defined period to see if the patient improves or deteriorates according to agreed-on clinical outcomes. If the patient improves, disease-directed therapy continues. If the patient deteriorates, the therapies involved in the trial are withdrawn, and goals frequently shift more purely to palliation. If significant clinical uncertainty remains, another TLT might be renegotiated. <http://jama.ama-assn.org/content/306/13/1483.extract>

Extract from a case study

Guiding patients facing decisions about "futile" chemotherapy

JOURNAL OF SUPPORTIVE ONCOLOGY, 2011;9(5):184-187. The palliative medicine team then met with the patient to discuss management options and her preferences for care ... [and] ... explained that her cancer was incurable but that chemotherapy options existed to help control her disease and possibly prolong her life. They also explained that the chemotherapy has side effects and that the patient would need to decide if she wanted to undergo treatment and accept potential side effects for the possibility of prolonging her life by weeks to months and improving her symptoms. As an alternative, she was told that she could focus solely on symptom control ... and allow her disease to take its natural course. <http://www.sciencedirect.com/science/article/pii/S1544679411000966>

Of related interest:

- *EMERGENCY MEDICAL JOURNAL* | Online article – 1 October 2011 – **'Palliative care for patients who died in emergency departments: Analysis of a multicentre cross-sectional survey.'** Palliative care is administered to about half of the patients who die in EDs [Emergency Departments]. <http://emj.bmj.com/content/early/2011/09/29/emered-2011-200513.abstract>

From Media Watch dated 3 October 2011:

- PENNSYLVANIA | *Inquirer* (Philadelphia) – 28 September 2011 – **'Palliative care comes to the emergency department.'** http://www.philly.com/philly/health_and_science/130678858.html
N.B. Additional articles from past issues of Media Watch on palliative care in the emergency department are footnoted.
- *MEDSCAPE MEDICAL NEWS* | Online report – 5 October 2011 – **'Patients frequently change advance directives at end of life.'** More than one third [of patients] change their orders toward the end of their life, meaning that clinicians should work with patients to re-evaluate their wishes, researchers reported at the [recent] European Respiratory Society Annual Congress. <http://www.medscape.com/viewarticle/750997>

The evolution of advance directives

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2011;306(13):1485-1486. There are two widely known problems with end-of-life care in the U.S. First, care often does not reflect patients' values and preferences. Second, end-of-life care constitutes a disproportionate amount of health care expenditures. There is a need to improve the value of health care spending because of changing economic and political climates and because Medicare and Medicaid costs account for nearly a quarter of the federal budget. Despite recognition that advance directives have conceptual limitations, their appeal persists because of the theoretical possibility that advance directives can simultaneously improve the patient centeredness of care and decrease health care expenditures near the end of life. The evolution of advance directives has mirrored that of many new medical technologies: initial unbridled enthusiasm evolved into skepticism as empirical evidence raised questions about the current practice, followed by a wiser, more constrained application. <http://jama.ama-assn.org/content/306/13/1485.extract>

The barriers to and evidence for palliative care

JOURNAL OF PEDIATRIC HEMATOLOGY/ONCOLOGY, 2011;33:S132-S135. It is undeniable that there are barriers to providing palliative care. Recent research suggests there is value in palliative care for patients, families, and those providing this care. Specifically, the research suggests that the earlier a patient receives palliative care, the better outcomes they will receive. First, this article will look at some of the barriers that sometimes prevent offering adequate palliative care to patient and families when the care is needed most. Second ... present results in a simplistic manner from actual research studies, which helps make the case through evidence of the value of palliative and quality end of life care. http://journals.lww.com/jpho-online/Abstract/2011/10001/The_Barriers_to_and_Evidence_for_Palliative_Care.13.aspx

N.B. This supplement to the *Journal of Pediatric Hematology/Oncology* includes several articles on palliative care. Contents page: <http://journals.lww.com/jpho-online/toc/2011/10001>

Treatment intensity at end of life – time to act on the evidence

THE LANCET | Online commentary – 6 October 2011 – Current health-care spending in the U.S. is unsustainable. Advances in expensive medical technologies and ageing of the population have resulted in soaring health-care costs. Medicare expenses in the last year of life are on average five times greater than non-terminal years, and vary substantially across geographical regions. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(11\)61420-7/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(11)61420-7/fulltext)

Withdrawal of medical treatment

LAW SOCIETY GAZETTE (U.K.) | Online OpEd – 4 October 2011 – Cases involving the withdrawal of medical treatment or, in some cases, the use of medical treatment against the wishes of a child or an adult without capacity are some of the most emotive cases that come before courts. There is a natural and widespread interest from members of the public about judges deciding whether a child or a vulnerable adult should continue to receive medical treatment. People wonder what they would do if faced with a similar set of circumstances or what they would want their relatives to do if they were in a similar situation. All of these cases involve incredible pressure on the relatives of the patient. The relatives, who are already under a great strain because of the condition of their loved one, are pitched into the court arena - often against doctors who are doing their best to make difficult decisions about withdrawing or refusing medical treatment which will then result in the death of the patient. The families in these cases understandably argue that they know the patient better than the treating doctors and are aware of what they would want or are aware of the patient's responses to things happening around them. <http://www.lawgazette.co.uk/in-practice/practice-points/withdrawal-medical-treatment>

Cont.

From Media Watch dated 3 October 2011:

- U.K. | *Daily Telegraph* – 28 September 2011 – '**Judge rejects family's right to die case.**' In the first case of its kind in this country, Mr. Justice Baker said that preservation of life was a fundamental principal of law. The woman's mother and sister had urged him to allow her to die, describing her "pointless existence" and saying she would not have wanted to live in such a state. But the judge found that the woman, identified only as "M," did have "some positive experiences" and crucially there was a "reasonable prospect" that those experiences could be extended.
<http://www.telegraph.co.uk/health/healthnews/8794013/Judge-rejects-familys-right-to-die-case.html>

Amyotrophic lateral sclerosis [ALS] and palliative care: Where we are, and the road ahead

MUSCLE & NERVE | Online article – Accessed 9 October 2011 – Patients with ALS have high symptom burdens including pain, fatigue, dyspnea, and sialorrhea, and they must make difficult decisions about the use of life-prolonging therapies such as long-term mechanical ventilation. The impact of this disease is also felt by family caregivers who often struggle to meet the heavy physical, financial and emotional demands associated with this illness. Expert multidisciplinary care may improve both quality and length of life of patients with ALS. However, while advances have been made in the treatment of some symptoms, others, including pain management, remain poorly studied. Involvement of palliative care specialists as part of the ALS multidisciplinary team is recommended, as we continue to work toward improving the quality of life for patients and their families. <http://onlinelibrary.wiley.com/doi/10.1002/mus.22305/abstract>

From Media Watch dated 14 February 2011:

- *JOURNAL OF NEUROLOGY, NEUROSURGERY & PSYCHIATRY* | Online article – 5 February 2011 – '**Palliative care in amyotrophic lateral sclerosis: Review of current international guidelines and initiatives.**' Despite an international consensus that ALS [amyotrophic lateral sclerosis] management should adopt a multidisciplinary approach, integration of palliative care ... varies considerably across health care systems. Late referral to palliative services in ALS is not uncommon and may impact negatively on the quality of life of ALS patients and their caregivers.
<http://jnnp.bmj.com/content/early/2011/02/04/jnnp.2010.232637.abstract?sid=2fb2379c-b7d2-419d-8a3b-bf6f757148c3>

From Media Watch dated 30 August 2010:

- AUSTRALIA | *The Record* – 24 August 2010 – '**Is there any 'frightening' disease palliative care can't deal with?**' Motor Neuron Disease, known as Lou Gehrig's disease [or amyotrophic lateral sclerosis (ALS)] ... is often more frightening than cancer for those who have it and their loved ones.
http://www.therecord.com.au/site/index.php?option=com_content&task=view&id=1929&Itemid=30

From Media Watch dated 7 June 2010:

- *AMYOTROPHIC LATERAL SCLEROSIS* | Online article – 17 March 2010 – '**Meaning in life in patients with amyotrophic lateral sclerosis.**' The aim of this study was to investigate 'meaning in life' in patients with amyotrophic lateral sclerosis and compare the findings with a ... sample of the German population. <http://informahealthcare.com/doi/abs/10.3109/17482961003692604>

Of related interest:

- *POSTGRADUATE MEDICAL JOURNAL* | Online article – 6 October 2011 – '**Evaluation of a new model of short-term palliative care for people severely affected with multiple sclerosis: A randomised fast-track trial to test timing of referral and how long the effect is maintained.**' In this ... trial, the authors examined 1) whether the timing of referral to short-term palliative care (PC) affected selected outcomes; and 2) the potential staff-modifying effect of the short-term PC intervention (whether the effects were sustained over time after PC was withdrawn). Receiving PC earlier has a similar effect on reducing symptoms but greater effects on reducing care giver burden, compared to later referral. In this phase II trial, the authors lacked the power to detect small differences. The effect of PC is maintained for 6 weeks after withdrawal but then appears to wane.
<http://pmj.bmj.com/content/early/2011/10/06/postgradmedj-2011-130290.abstract>

Cont.

- *PROGRESS IN PALLIATIVE CARE*, 2011;19(5):230-234. '**A symptom-based approach to palliative care in cystic fibrosis [CF].**' The increase in life expectancy has been accompanied by an increase in both chronic and acute physical and psychological symptoms. Careful attention to symptom assessment and treatment should now be a routine aspect of care for children and adults with CF. Although life expectancy has increased dramatically, children and adults with CF will still die before their unaffected peers, and careful attention to issues in end-of-life care is still a part of CF care, with the often complicating factor of lung transplantation as a relatively recent arrival. <http://www.ingentaconnect.com/content/maney/ppc/2011/00000019/00000005/art00003>

England's End-of-Life Care Strategy

[Health secretary Andrew] Lansley brings forward deadline for new palliative care funding regime

NURSING TIMES | Online report – 3 October 2011 – Health secretary Andrew Lansley ... wants a new system of per-patient funding for end of life care in place by 2015, a year earlier than was recommended in the Palliative Care Funding Review.¹ The review, which reported earlier this year, said the new system would reduce variation in access to palliative care across England, incentivise the development of community services, and be fair to patients in all settings, whether in hospitals, care homes, hospices, or at home. Addressing the Help the Hospices' conference, Mr. Lansley said: "We have an opportunity to give people the best care at the end of their lives. We need to push forward with reform and I want a new system in place by 2015, moving forward faster than the review proposed." But the charity's chief executive, David Praill, warned the intervening years would be a "period of unprecedented change" in healthcare, and palliative care providers would need protection. "We cannot risk destabilising the current provision of funding, which would have serious implications for people facing the end of life and their friends and family," he said. <http://www.nursingtimes.net/nursing-practice/clinical-specialisms/end-of-life-and-palliative-care/lansley-brings-forward-deadline-for-new-palliative-care-funding-regime/5035818.article>

1. *Palliative Care Funding Review Interim Report*, December 2010. (Noted in Media Watch dated 17 January 2011). <http://www.palliativecarefunding.org.uk/InterimReport.pdf>

Of related interest:

- U.K. | Department of Health – 4 October 2011 – '**Patients to have a greater say and choice over their care.**' People receiving continuing healthcare support from the National Health Service [NHS] will have the right to ask for a personal health budget. It will give the tens of thousands of people who receive NHS Continuing Healthcare more choice and control over their care. <http://mediacentre.dh.gov.uk/2011/10/04/patients-to-have-greater-say-choice-over-care/>
- THE KING'S FUND | Online report – Accessed 3 October 2011 – '**Issues facing commissioners of end-of-life care.**' This report proposes that the personalized, clinically led and integrated delivery of end-of-life care should be supported through alternative approaches to funding and commissioning (see sidebar right). Current ... mechanisms are inadequate for meeting the needs of patients as they near the end of life. More appropriate approaches can be encouraged by developing a tariff for a pathway or package of care, with local commissioners specifying outcome measures and encouraging integration through service contracts. http://www.hc2d.co.uk/doclibrary/documents/pdf/767_issues_facing.pdf

The ... government has proposed a new structure ... under which primary care trusts will be abolished in 2013 and be replaced by clinical commissioning groups. These groups will have responsibility for managing National Health Service resources and commissioning services for local populations.

From Media Watch dated 3 October 2011:

- U.K. (ENGLAND) | Department of Health – 26 September 2011 – '**End of Life Care Strategy: 3rd Annual Report.**' http://www.endoflifecareforadults.nhs.uk/assets/downloads/dh_130253.pdf

Worth Repeating

More than trivial: Strategies for using humor in palliative care

CANCER NURSING, 2005;28(4):292-300. Humor and laughter are ubiquitous in human interactions. Terminal illness, however, is often accompanied by circumstances of anxiety, fear, and sadness. Hospice/palliative care emphasizes quality of life and the importance of human relationships. In this context, humor finds its place in authentic person-to-person connectedness. This article presents findings from a clinical ethnography that investigated the phenomena of humor and laughter in an inpatient palliative care unit. Humor was pervasive, varied in the setting, and occurred across a range of intensities. Both clients and team members used humor to build relationships, contend with circumstances, and express sensibilities. Humor was affected by differences in people, differing circumstances, ethnicity, gender, and degree of stress. Participants relied on intuition as well as a constellation of other factors in discerning whether or not to use humor. Techniques for assessment included identification of cues such as expression in the eyes and timing as indications of receptivity. Combined with caring and sensitivity, humor is a powerful therapeutic asset in hospice/palliative care. It must neither be taken for granted nor considered trivial. <http://xa.yimg.com/kq/groups/20503861/1218652787/name/033105-humor-in-palliative-care.pdf>

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy tool or change document.

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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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