

Media Watch...

is intended as an advocacy and research tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in hospice and palliative care, and in the quality of end-of-life care in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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To be ready to die with life: Scroll down to [Specialist Publications](#) and 'The temenos of palliative care' (p.8), in *Psychological Perspectives*.

Canada

Elder care in Québec

Homecare lacks consistency, report finds

QUÉBEC | *The Montreal Gazette* – 5 June 2013 – Health & Social Services Minister Réjean Hébert's prescription to bring down costs and improve care for seniors, is not living up to its billing, says the latest report by Québec's auditor general. "We have a system," acting auditor-general Michel Samson told reporters, but that system lacks direction and standards. The auditor-general and his team looked at homecare services in Ahuntsic and Montreal North, as well as Gatineau and rural Lanaudière. They found that each CSSS [Centres de santé et de services sociaux], or health and social services centre, set its own standards. There were wide variations in access to services and the length of time they were available, Samson explained. Hébert's department

says that with Québec's rapidly aging population, the province is developing new approaches favouring homecare "to improve the quality of services for seniors and adults with reduced autonomy." In Québec, 54% of those receiving homecare are seniors, while 46% are adults with reduced autonomy. <http://www.montrealgazette.com/life/Homecare+lacks+consistency+report+finds/8481765/story.html>

[Specialist Publications](#)

'End of life care in Canada: A report from the Canadian Academy of Health Sciences Forum' (p.13), in *Clinical & Investigative Medicine*.

N.B. French and English language versions of the provincial auditor general's report available at: http://www.vgq.qc.ca/en/en_publications/en_rapport-annuel/en_index.aspx

Noted in Media Watch, 3 June 2013:

- QUÉBEC | CTV News (Montréal) – 30 May 2013 – 'Parti Québécois pushes home care as solution to exploding medical costs.' According to projections, the \$4 billion the province currently spends each year on long term care could triple in 15 years. Each patient treated at home costs on average, \$30,000/year versus triple that cost for someone in hospital full time. <http://montreal.ctvnews.ca/pq-pushes-home-care-as-solution-to-exploding-medical-costs-1.1304573>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUÉBEC | CBC News (Montreal) – 5 June 2013 – **'Dying with dignity legislation to be tabled at national assembly.'** The Québec government is expected to table its "dying with dignity" legislation in the coming days. The law would allow certain forms of medical aid in dying – also called "assisted suicide" by some. In a 2012 report ... Québec's Committee on Dying with Dignity said "given the large turnout at the hearings, it is clear that Quebecers were ready for this debate and felt it was important." The federal government has made it clear it has no intention of changing the law, announcing last summer it would appeal a June ruling by British Columbia's Supreme Court that partially struck down a ban on assisted suicide. But Québec has decided to forge ahead. <http://www.cbc.ca/news/canada/montreal/story/2013/06/05/montreal-dying-with-dignity-assisted-suicide-legislation-law-quebec.html>

1. *La Commission spéciale sur la question de mourir dans la dignité dépose son rapport*, Select Committee of the Québec National Assembly, March 2012. [Noted in Media Watch, 26 March 2012]

French language edition: <http://www.assnat.qc.ca/fr/actualites-salle-presse/nouvelle/Actualite-25939.html>;

English language edition:
http://www.worldrtd.net/sites/default/files/newsfiles/Quebec_Report%20in%20English.pdf

U.S.A.

Is behavioral economics the death of living wills?

FORBES | Online – 9 June 2013 – Everyone should make sure they're comfortable about who will make decisions for them if they are unable to decide for themselves. Generally speaking, if you are unable to decide for yourself, the hospital personnel will turn to your next of kin – your spouse if you have one, your adult child if you are a widow or widower. But if you don't want that next of kin to be your decision maker, or if you have multiple children and you want to make sure the doctors know which one to turn to, you need to get yourself a *Durable Power Of Attorney for Healthcare*. I know that is a clunky legalistic phrase. But here is what it means. It means you are telling your physician who you want making decisions for you if you are not able to participate in those decisions. If you are delirious or unconscious because of a health problem, your doctors will know who they can talk to to make decisions about your health care. <http://www.forbes.com/sites/peterubel/2013/06/09/is-behavioral-economics-the-death-of-living-wills/>

"Owning up to uncertainty"

Uncertainty is hard for doctors

THE NEW YORK TIMES | Online commentary – 6 June 2013 – As a group, doctors dislike ambiguity. We pride ourselves in the scientific girders of modern medicine. We are most comfortable when we are dispensing medical care to our patients that comes from a double-blind clinical trial that fits into a validated clinical-prediction rule that derives from an accepted algorithm and has 'Level 1' evidence behind it. But, very little of medicine falls into that absolute category. Many of our treatments haven't been rigorously studied, and even if they have, large swaths of the population are woefully underrepresented in clinical trials – the very old, the very sick, women, members of racial and ethnic minorities, children, pregnant women and those low on the socioeconomic scale. Much of the time, therefore, we function in an ambiguous zone, without clear-cut answers. <http://well.blogs.nytimes.com/2013/06/06/uncertainty-is-hard-for-doctors/?ref=health>

The cost and quality conundrum of American end-of-life care

THE MEDICARE NEWS GROUP | Online – 3 June 2013 – At first glance, America is making great strides toward a medical and cultural shift in its approach to end-of-life care: more and more providers are recognizing the benefits of hospice, more people are dying at home, and many health care organizations are institutionalizing the discussions between providers and patients that would help patients formalize their wishes for end-of-life care through an advance directive. But pull up the curtain on these statistics, and the drama that unfolds tells a very different story. End-of-life care continues to be characterized by aggressive medical intervention and runaway costs. Like so many other problems plaguing the financing and quality of health care in America, the end-of-life dilemma is rooted in Medicare's fee-for-service payment structure, says Joan M. Teno, MD, lead author of a recent study.¹ <http://medicarenewsgroup.com/context/understanding-medicare-blog/understanding-medicare-blog/2013/06/03/the-cost-and-quality-conundrum-of-american-end-of-life-care>

Medicare could save millions by implementing a hospital transfer payment policy for early discharges to hospice care

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES | Office of the Inspector General – 28 May 2013 – Medicare could have saved \$602.5 million for calendar years 2009 and 2010 by applying a hospital transfer payment policy for early discharges to hospice care. Medicare payments based on a *per diem* rate rather than a full payment for the sampled claims would have resulted in \$380,000 in savings. Approximately 30% of all hospital discharges to hospice care were early discharges that would have received per diem payments rather than full payments under a hospital transfer payment policy. In addition, this transfer payment policy would not have caused a significant financial disadvantage for hospitals or disproportionately affected any hospital. <https://oig.hhs.gov/oas/reports/region1/11200507.asp>

1. 'Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and health care transitions in 2000, 2005, and 2009,' *Journal of the American Medical Association*, 2013; 309(5):470-477. Among Medicare beneficiaries who died in 2009 and 2005 compared with 2000, a lower proportion died in an acute care hospital, although both ICU use and the rate of health care transitions increased in the last month of life. [Noted in Media Watch, 11 February 2013] <http://jama.jamanetwork.com/article.aspx?articleid=1568250>

Of related interest:

- *THE MEDICARE NEWS GROUP* | Online – 3 June 2013 – **'End-of-life care constitutes third rail of U.S. health care policy debate.'** Any debate about health care policy isn't complete without adequately addressing its third rail – end-of-life care – and the financial stress it puts on the Medicare budget. Total federal spending on health care eats up nearly 18% of the nation's output, about double what most industrialized nations spend on health care. In 2011, Medicare spending reached close to \$554 billion, which amounted to 21% of the total spent on U.S. health care in that year. Of that \$554 billion, Medicare spent 28%, or about \$170 billion, on patients' last six months of life. <http://medicarenewsgroup.com/context/understanding-medicare-blog/understanding-medicare-blog/2013/06/03/end-of-life-care-constitutes-third-rail-of-u.s.-health-care-policy-debate>

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[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>

- *THE MEDICARE NEWS GROUP* | Online – 3 June 2013 – **'Time is ripe to address end-of-life care in Medicare, some experts say.'** End-of-life policymaking may be as inevitable as death itself – an issue that lawmakers may fear and loathe, but one that is unlikely to ever go away. The "death panel" debate that circled an early provision of the Affordable Care Act that would have provided payment to physicians for advance planning and end-of-life consultations was like a vulture trying to kill its prey. But while it may have temporarily squashed the issue (the provision was stricken from the bill that became law), the costs, ethics and concerns about end-of-life care will not let the topic die. <http://medicarenewsgroup.com/context/understanding-medicare-blog/understanding-medicare-blog/2013/06/03/time-is-ripe-to-address-end-of-life-care-in-medicare-some-experts-say>

Specialist Publications

'Trends in length of hospice care from 1996 to 2007 and the factors associated with length of hospice care in 2007: Findings from the National Home & Hospice Care Surveys' (p.8), in *American Journal of Hospice & Palliative Care*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *The Sacramento Bee* – 4 June 2013 – **'More than 65% of family caregivers support the legalization of physician-assisted suicide.'** AgingCare.com conducted a survey to gauge sentiment among those who are closest to the patients for whom the bill is primarily intended to help: the terminally ill elderly who are near death, without hope of recovery. <http://www.sacbee.com/2013/06/04/5469241/more-than-65-of-family-caregivers.html>

International

End-of-life care in New Zealand

Closure is blow for end-of-life patients

NEW ZEALAND | *The Manawatu Standard* (Palmerston North) – 7 June 2013 – The closure of the national headquarters that supports end-of-life facilities could impact on the way dying patients are treated. Insufficient funding has meant the national Liverpool Care Pathway office is closing its doors – leaving more than 350 registered end-of-life organisations with no co-ordinator in New Zealand. Arohanui Hospice chief executive Clare Randall said the closure of the national office was a shame but no stone was left unturned in the effort to secure an annual \$300,000. "We are working with the ministry to ensure there are communications out to the facilitators across the country to ensure they are supported to continue to deliver the programme regionally," she said. <http://www.stuff.co.nz/manawatu-standard/news/8767808/Closure-is-blow-for-end-of-life-patients>

Specialist Publications

'Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe' (p.8), in *Palliative Medicine*.

'The Melbourne Family Support Program: Evidence-based strategies that prepare family caregivers for supporting palliative care patients' (p.9), in *BMJ Supportive & Palliative Care*.

'Improving the quality of life of terminally ill oncological patients: The example of palliative care at Hospice Villa Speranza' (p.14), in *Future Oncology*.

'Withholding and withdrawal of "futile" life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand' (p.15), in *Journal of Law & Medicine*.

Cont.

Of related interest:

- NEW ZEALAND | *Hawke's Bay Today* (Hastings) – 5 June 2013 – '**Cranford funding cut horrifies.**' Cranford Hospice is reeling from an estimated \$193,000 funding cut as the Hawke's Bay District Health Board [DHB] tightens its purse strings. The Hastings hospice's chairman, Ken Gilligan, said the cut was "a huge amount" for a charity that already had a shortfall of \$2 million a year. He said the hospice may have been targeted because it had managed to run a surplus for the past two financial years. <http://www.hawkesbaytoday.co.nz/news/cranford-funding-cut-horrifies/1895335/>

Half of U.K. population "will get cancer in lifetime"

U.K. | BBC News – 6 June 2013 – The number of people in the U.K. who will get cancer during their lifetime will increase to nearly half the population by 2020, a report has forecast.¹ Macmillan Cancer Support said the projected figure of 47% would put huge pressure on the NHS [National Health Service]. Yet those who do develop cancer will be less likely to die from the disease, the charity predicted. In 1992, the proportion of people in the U.K. who got cancer during their life was 32%. This increased to 44% in 2010, an increase of more than a third. Macmillan said this figure would continue rising over the next decade, levelling off at around 47% between 2020 and 2030. <http://www.bbc.co.uk/news/health-22796220>

1. 'Cancer mortality trends: 1992-2020,' Macmillan Cancer Support, May 2013. <http://www.macmillan.org.uk/Documents/AboutUs/Newsroom/Mortality-trends-2013-executive-summary-FINAL.pdf>

Cost of dying "as high as £7,000"

U.K. | *The Express & Star* (Wolverhampton) – 6 June 2013 – The cost of dying can be as high as £7,000 when funerals and other costs such as flowers and wakes are added up, according to a study. The GMB [Britain's General Union] said the most expensive burials were in Lambeth, London, at £5,329, and the City of London (£5,185), while crematoriums cost £3,464 in the City of London. Paul Kenny, general secretary of the GMB, told the union's annual conference in Plymouth: "At a time when the cost of living occupies most people's concerns, it will be a real shock to many that the cost of dying is so high. While GMB realises that the public are not queuing up to test the services, it remains a fact that few have any idea of how much even a simple burial or cremation actually costs. Someone is making a lot of money out of people's bereavement." <http://www.expressandstar.com/business/uk-money/2013/06/06/cost-of-dying-as-high-as-7000/>

N.B. GMB study: <http://www.gmb.org.uk/newsroom/cost-of-dying>

End-of-life care in Australia

"Impending crisis" for vital service

AUSTRALIA (NEW SOUTH WALES) | *The Newcastle Herald* – 4 June 2013 – Hunter [region] health groups have said they are hitting a "wall of silence" on the future of a critical palliative care service. Federal government seed funding for 55 specialist community health professionals statewide, including 14 in the Hunter [region], runs out on 30 June. Under the conditions of a joint agreement, the state government was expected to take over but has yet to commit to funding the positions. The 14 Hunter-Central Coast-based positions include community care specialists such as nurses, staff specialists, a registrar and an Aboriginal health officer. They help about 1,500 families in the region each year. <http://www.theherald.com.au/story/1546920/impending-crisis-for-vital-service/?cs=2373>

Cont.

Noted in Media Watch, 27 May 2013:

- AUSTRALIA (TASMANIA) | ABC News – 22 May 2013 – **'Big cash injection for palliative care.'** The Federal Government has announced what it says is the biggest ever injection of money into Tasmania's palliative care sector. <http://www.abc.net.au/news/2013-05-22/big-cash-injection-for-palliative-care/4706108>

Noted in Media Watch, 25 February 2013:

- AUSTRALIA (NEW SOUTH WALES) | *The Daily Telegraph* (Surrey Hills) – 25 February 2013 – **'Terminally ill suffer as federal palliative funds dry up.'** Terminally ill cancer patients and the elderly will be left without specialised end-of-life care from July when a \$500 million program at the heart of Prime Minister Julia Gillard's health care reforms finishes. <http://www.dailytelegraph.com.au/news/terminally-ill-suffer-as-federal-palliative-funds-dry-up/story-e6freuy9-1226584565780>

End-of-life care in Ireland

Patients die in hospital as hospice beds lie idle

IRELAND | *The Herald* (Dublin) – 4 June 2013 – Dying patients are being forced to spend their last days in hospitals while a quarter of the country's hospice beds lie idle. Blanchardstown councillor David McGuinness of [the political party] Fianna Fail has hit out at the continued refusal by government to provide funding for new hospice beds which are not being used. In his own constituency, 24 beds at St. Francis Hospice intended for terminally ill patients with cancer, motor neurone disease and AIDS have never opened since they were built because of funding. A further 22 beds are closed at the Marymount Hospice in Cork since the facility opened in 2011. Mr. McGuinness said these beds were sanctioned by the HSE [Health Services Executive] because they were needed. Chief executive of the Irish Hospice Foundation, Sharon Foley, has described as "unacceptable" the fact that beds provided from public charitable donations are lying idle. She explains that 12 counties have no in-patient hospice beds whatsoever. The areas worst affected include the North-east, South-east, the Midlands as well as Mayo, Wicklow and Kerry. <http://www.herald.ie/news/patients-die-in-hospital-as-hospice-beds-lie-idle-29316465.html>

Elder care in Ireland

Cutbacks and privatisation the order of the day in State strategy for care of elderly

IRELAND | *The Irish Times* (Dublin) – 5 June 2013 – Tighter regulation of home help and homecare services for older people was promised in the programme for government but has yet to be delivered. But this is only one of a number of commitments in the document affecting older people that have been broken, or have not yet been fulfilled. More funding was promised each year, which would in turn provide more residential places, more homecare package and more home help hours. Instead, there were cuts last year in the number of home help hours and homecare packages. At one point, it looked as though almost one million home help hours would be cut from a total of 10 million hours, but according to the Health Service Executive Plan ... the actual reduction was about 200,000 hours. <http://www.irishtimes.com/news/social-affairs/cutbacks-and-privatisation-the-order-of-the-day-in-state-strategy-for-care-of-elderly-1.1417198>

Cont.

Noted in Media Watch, 13 May 2013:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(3):130-133. **'Challenges in increasing regional equity in palliative care service provision in Ireland.'** This article reports on regional inequity after a decade of funding and policy changes. It arose out of a larger study funded by The Atlantic Philanthropies, whose 'End of Life' programme has contributed significantly to hospice and palliative care in the Republic of Ireland.¹

1. *Evaluation: Programme to Support Palliative and Hospice Care in the Republic of Ireland: Final Report*, The Atlantic Philanthropies, 2013. [Noted in Media Watch, 21 January 2013] http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation_Programme_Support_Palliative_and_Hospice_Care_%20Republic_of_Ireland.pdf

Noted in Media Watch, 15 April 2013:

- IRELAND | *The Irish Examiner* (Lapps Quay, Cork) – 10 April 2013 – **'Dignity, when it's needed most.'** According to Irish Hospice Foundation research, 43% of us die in acute hospital settings. Seven in 10 want to die at home but – for many of us – that wish is not fulfilled. <http://www.irishexaminer.com/lifestyle/features/dignity-when-its-needed-most-227884.html>

N.B. Irish Hospice Foundation's 'Competence & Compassion: End-of-Life Care' map provides a set of key considerations for staff in end-of-life care: how doctors can recognise a progressive deterioration in health; diagnosing dying; communicating in difficult circumstances; planning end of life care with patients; communicating CPR decisions; and, caring for a deceased patient. http://www.hospicefriendlyhospitals.net/media/k2/attachments/End_of_Life_Care_Map_Print_friendly_version_1.pdf

U.S. talking sessions will help combat compassion fatigue in healthcare staff

U.K. | *The Guardian* – 4 June 2013 – American-style hospital sessions, called Schwartz [Centre] rounds, where staff from different disciplines come together to discuss their feelings about their jobs to help combat stress, are being rolled out to 55 hospitals in the U.K. Nurses and care workers in the National Health Service, particularly those caring for elderly patients, can frequently be punched, pinched, shouted at and racially abused – a fact that may shock as it is not generally spoken about. This can desensitise you and make you a less compassionate person. <http://www.guardian.co.uk/society/2013/jun/04/us-strategy-combat-compassion-fatigue-healthcare>

N.B. The Schwartz Center Rounds program offers healthcare providers a regularly scheduled time during their fast-paced work lives to openly and honestly discuss social and emotional issues that arise in caring for patients. In contrast to traditional medical rounds, the focus is on the human dimension of medicine. <http://www.theschwartzcenter.org/viewpage.aspx?pageid=20>. See also: 'The Schwartz Center Rounds: Evaluation of an interdisciplinary approach to enhancing patient-centered communication, teamwork, and provider support,' *Academic Medicine*, 2010;85(6):1073-1081. http://journals.lww.com/academicmedicine/Fulltext/2010/06000/The_Schwartz_Center_Rounds_Evaluation_of_an.37.aspx?ref=nf

Noted in Media Watch, 24 December 2012:

- *NURSING IN PRACTICE* | Online – 18 December 2012 – **'National Health Service to implement Chief Nursing Officer vision of compassionate care.'** The NHS [National Health Service] will drive forward a culture of compassionate care as set out by the NHS's Commissioning Board's chief nursing officer.¹ <http://www.nursinginpractice.com/article/nhs-implement-cno-vision-compassionate-care>

1. *Everybody counts: Planning for patients 2013/14*, National Health Service Commissioning Board, December 2012. <http://www.commissioningboard.nhs.uk/everyonecounts/>

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

End-of-life care in the U.S.

Trends in length of hospice Care from 1996 to 2007 and the factors associated with length of hospice care in 2007: Findings from the National Home & Hospice Care Surveys

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE | Online – 6 June 2013 – Using the National Home & Hospice Care Surveys, the authors examined trends in the length of hospice care from 1996 to 2007 and the factors associated with the length of care in 2007. Results suggest that the increasing average lengths of care over time reflect the increase in the longest duration of care. For-profit ownership is associated with hospice care received for over a year. <http://ajh.sagepub.com/content/early/2013/06/05/1049909113492371.abstract>

End-of-life care in Europe

Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe

BMC FAMILY PRACTICE | Online – 3 June 2013 – Although end-of-life care has become an issue of great clinical and public health concern in Europe and beyond, we lack population-based nationwide data that monitor and compare the circumstances of dying and care received in the final months of life in different countries. The European Sentinel GP Networks Monitoring End of Life Care (EURO SENTIMELC) study was designed to describe and compare the last months of life of patients dying in different European countries [Belgium, The Netherlands, Italy and Spain]. The authors describe how representative GP networks in the EURO SENTIMELC study operate to monitor end of life care in a country, to describe used methodology, research procedures, representativity and characteristics of the population reached using this methodology. <http://www.biomedcentral.com/content/pdf/1471-2296-14-73.pdf>

The *temenos* of palliative care

PSYCHOLOGICAL PERSPECTIVES, 2013; 56(2):212-220. Serious illness puts us in touch with an acute sense of our own vulnerability and mortality. Loss of ego identity creates an urgent longing to find meaning within the experience of illness or impending death. Inspired by his own near-death experiences in later life, Jung wrote about the goal of the second half of life: "to be ready to die with life." This article reflects upon three individuals' stories illustrating how palliative care embraces the needs of the whole person and prepares individuals to participate consciously in their final journey in life. This inter-professional model of care can help individuals and their loved ones experience the highest quality of life possible and bring completion to life's relationships. These stories demonstrate a synergy between Jung's beliefs regarding the goal of the second half of life and the soul work necessary for healing, wholeness, and individuation. <http://www.tandfonline.com/doi/abs/10.1080/0032925.2013.786977#.UbChq9JwomY>

Representative sample of recent articles on end-of-life care in Europe noted in Media Watch:

- EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online – 29 May 2013 – '**Atlas of palliative care in Europe 2013.**' The aim of this study is to provide an updated, reliable and comprehensive analysis on the development of palliative care within each European country. http://issuu.com/universidaddenavarra/docs/atlas_europa_full_edition
- *PALLIATIVE MEDICINE* | Online – 23 May 2013 – '**Priorities for treatment, care and information if faced with serious illness: A comparative population-based survey in seven European countries.**' The authors examined variations in people's priorities for treatment, care and information across seven European countries [i.e., England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain]. In total, 9,344 individuals were interviewed. <http://pmj.sagepub.com/content/early/2013/05/23/0269216313488989.abstract>

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- *PSYCHO-ONCOLOGY* | Online – 18 March 2013 – '**If you had less than a year to live, would you want to know? A seven-country European population survey of public preferences for disclosure of poor prognosis.**' Among 9344 respondents [to this population based survey], data revealed an international preference (73.9%) to always be informed in the scenario of having a serious illness such as cancer with less than a year to live. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3283/abstract>
- *EUROPEAN JOURNAL OF PUBLIC HEALTH* | Online – 13 March 2013 – '**Learning from the public: Citizens describe the need to improve end-of-life care access, provision and recognition across Europe.**' Despite ageing populations and increasing cancer deaths, many European countries lack national policies regarding palliative and end-of-life care. <http://eurpub.oxfordjournals.org/content/early/2013/03/13/eurpub.ckt029.abstract>
- *BMC CANCER* | Online – 8 March 2013 – '**Burden to others' as a public concern in advanced cancer: A comparative survey in seven European countries.**' Pain was the top concern in all countries, from 34% participants (Italy) to 49% (Flanders). Burden was second in England, Germany, Italy, Portugal, and Spain. Breathlessness was second in Flanders and The Netherlands. <http://www.biomedcentral.com/content/pdf/1471-2407-13-105.pdf>
- *EUROPEAN JOURNAL OF CANCER* | Online – 18 February 2013 – '**Awareness of general practitioners concerning cancer patients' preferences for place of death: Evidence from four European countries.**' Despite the importance of being able to die in a preferred location, GPs [i.e., study participants] were often unaware about patient preferences, especially in Italy and Spain. If GPs were informed, the preference was often met in all countries, indicating room for improvement in end-of-life care. [http://www.ejancer.info/article/S0959-8049\(13\)00044-0/abstract](http://www.ejancer.info/article/S0959-8049(13)00044-0/abstract)

The Melbourne Family Support Program: Evidence-based strategies that prepare family caregivers for supporting palliative care patients

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 4 June 2013 – Four psycho-educational interventions, incorporating one-to-one and group format delivery, conducted in both the home and inpatient hospital/hospice were evaluated. Statistically significant outcomes included improvements in family caregivers' preparedness, competence, positive emotions, more favourable levels of psychological wellbeing and a reduction in unmet needs. Internationally endorsed guidelines for the psychosocial support of family caregivers were produced and several resources were constructed. Fifteen publications in international peer-reviewed journals have arisen from this programme. The interventions and resources from the Melbourne Family Support Program provide several evidenced-based and clinically relevant approaches that focus on reducing the psychosocial burden of the caregiving role. <http://spcare.bmj.com/content/early/2013/06/04/bmjspcare-2013-000500.abstract>

Discontinuity of care at end of life: A qualitative exploration of out of hours end of life care

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 7 June 2013 – This study aimed to understand the experiences of palliative care patients when accessing or making decisions about out of hours (OOH) services. [Study] participants described the importance of being known by the healthcare team, and the perceived positive implications continuity could have for the quality of care they received and the trust they had in their care. Various factors prevented participants from seeking help or advice, despite having health concerns that may have benefitted from medical assistance. Prior poor experience, limited knowledge of services and knowing who to call and, indeed, when to call were all factors that reportedly shaped participants' use of OOH services. <http://spcare.bmj.com/content/early/2013/06/07/bmjspcare-2012-000266.abstract>

Cont.

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 5 June 2013 – '**Effect of a home-based end-of-life nursing service on hospital use at the end of life and place of death: A study using administrative data and matched controls.**' Home-based end-of-life care offers the potential to reduce demand for acute hospital care and increase the number of people able to die at home. <http://spcare.bmj.com/content/early/2013/06/05/bmjspcare-2012-000424.abstract>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 3 June 2013 – '**Hospice caregivers' experiences with pain management: "I'm not a doctor, and I don't know if I helped her go faster or slower."**' The findings [of this study] should raise concern among hospice professionals, whose commitment is to the management of pain, including emotional pain, with a focus on both the patient and the family as a unit of care. Data clearly suggest hospice providers have opportunity to be sensitive to perceptions held by caregivers regarding pain management. [http://www.jpsmjournal.com/article/S0885-3924\(13\)00228-5/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00228-5/abstract)
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 May 2013 – '**Feasibility and preliminary effects of an Intervention Targeting Schema Development for Caregivers of newly admitted hospice patients.**' Caregivers who completed the intervention program rated the program very good or excellent, thought the information was helpful and timely, and would recommend it to friends. <http://online.liebertpub.com/doi/full/10.1089/jpm.2012.0198>

Representative sample of recent articles on the preparedness for family caregiving noted in Media Watch:

- *PALLIATIVE MEDICINE* | Online – 21 May 2013 – '**Family caregiver learning – how family caregivers learn to provide care at the end of life: A qualitative secondary analysis of four datasets.**' Family caregivers learn through trial and error, actively seeking needed information and guidance, applying knowledge and skills from previous experience, and reflecting on... <http://pmj.sagepub.com/content/early/2013/05/20/0269216313487765.abstract>
- *PALLIATIVE MEDICINE* | Online – 13 May 2013 – '**Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: A correlational, cross-sectional study.**' The authors' findings support the inclusion of preparedness in support models for family caregivers in palliative care. <http://pmj.sagepub.com/content/early/2013/05/03/0269216313486954.abstract>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 13 December 2012 – '**The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: A validation study.**' Family carers need to be supported in their central role of caring for patients at the end of life, but brief practical tools to assess their support needs have been missing. [http://www.jpsmjournal.com/article/S0885-3924\(12\)00750-6/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00750-6/abstract)
- *QUALITY HEALTH RESEARCH*, 2012;22(7):1007-1015. '**"It's like we're grasping at anything": Caregivers' education needs and preferred learning methods.**' Four categories of educational needs were identified: a) respite; b) caregiving essentials; c) self-care; and, d) the emotional aspects of caregiving. <http://qhr.sagepub.com/content/22/7/1007.abstract>



[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.ipccr.net/barry-r-ashpole.php>

Assessing the uptake of The Liverpool Care Pathway for dying patients: A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 25 May 2013 – A comprehensive systematic review was conducted for papers published between January 1990 and July 2012 providing information on the LCP [Liverpool care Pathway] uptake. 17 papers met inclusion criteria. A total of 18,052 patients were placed on the LCP, in a variety of inpatient and primary care settings, and cancer and non-cancer diagnoses. 47.4% of dying patients identified were placed on the LCP. Although the LCP is widely recommended, it is only used for around half of dying patients. Reasons may include lack of knowledge, high staff turnover and concerns about applicability particularly for unpredictable dying trajectories. The proportion of patients who meet the eligibility criteria and the reasons surrounding low uptake remain unclear. Research is urgently required to further quantify the variable use of the LCP, and to investigate whether alternative approaches should be developed for non-cancer groups. <http://spcare.bmj.com/content/early/2013/05/25/bmjspcare-2012-000406.abstract>

Of related interest:

- *JOURNAL OF THE INTENSIVE CARE SOCIETY*, 2013;14(2):100-103. **'The future of The Liverpool Care Pathway in caring for the dying in intensive care.'** The LCP should have been associated with high quality, considerate, informed and compassionate end-of-life care. Instead, it has become associated with ill-considered, didactic decision making, with lack of communication and lack of empathy; we would do well to consider the lessons very broadly. <http://journal.ics.ac.uk/pdf/1402100.pdf>

Cont. next page

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 and research tool.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
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3. Access to a complete article, in some cases, may require a subscription or one-time charge.
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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

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.

Noted in Media Watch, 3 June 2013:

- **PULSE (U.K.) | Online – 30 May 2013 – 'GPs avoiding Liverpool Care Pathway "due to adverse publicity.'** Negative publicity surrounding the LCP is causing some GPs to avoid using it in patients nearing the end of their lives, the Royal College of General Practitioners has told a Government review into the pathway. <http://www.pulsetoday.co.uk/clinical/therapy-areas/pain-relief/gps-avoiding-liverpool-care-pathway-due-to-adverse-publicity-says-rcgp/20003120.article#.UadUGNJwomY>

N.B. Footnoted is representative sample of recent articles on the LCP noted in Media Watch.

The death of my dog: Lessons learned from the palliative care of an animal

BRITISH JOURNAL OF GENERAL PRACTICE, 2013;63(611):317. Abstract or link to article unavailable. <http://www.ingentaconnect.com/content/rcgp/bjgp/2013/00000063/00000611/art00022>

Noted in Media Watch, 11 February 2013:

- U.S. | *The Star Tribune* (Minneapolis, Minnesota) – 4 February 2013 – **'Letting a loved one go – pet or person.'** When asked whether it was time to put Byron "to sleep," our vet said he used the 50% rule: Were at least half of Byron's days good days? Or was it two bad days for every good? <http://www.startribune.com/opinion/commentaries/189740661.html?refer=y>

Noted in Media Watch, 16 April 2012:

- U.S. | *The New York Times* – 9 April 2012 – **'An ethical quandary, no matter the species.'** Crucial conversations between veterinarians and pet owners are most helpful. And perhaps our consideration of these issues for our pets will foster more discussion of these vital matters in the treatment and end-of-life care for our human loved ones and ourselves. <http://www.nytimes.com/roomfordebate/2012/04/09/the-ethics-of-spending-25000-on-pet-health-care/an-ethical-quandary-no-matter-the-species>

Towards a social model of end-of-life care

BRITISH JOURNAL OF SOCIAL WORK | Online – 30 May 2013 – This paper challenges the social work profession to consider whether the hospice and palliative care model needs to be rethought; argues that social work is well positioned to help develop a more adequate model of care; and recommends a social model that builds upon the resources and networks already surrounding individuals. The social work profession is well placed to draw upon its values, culture and experience (particularly from the service user movement) and to get involved in developing new models of end-of-life care. This paper argues the benefits of community engagement through network mobilisation. <http://bjsw.oxfordjournals.org/content/early/2013/05/29/bjsw.bct087.abstract>

Of related interest:

- *JOURNAL OF SYSTEMIC THERAPIES*, 2013;32(1):56-69. **'A community approach to palliative care: Embracing indigenous concepts and practices in a hospice setting.'** This article documents a community approach to palliative care that took place in Auckland, Aotearoa New Zealand in 2010. While the hospice organization that coordinated the care under discussion ordinarily engages a wide range of social work, medical, nursing, and family services, in this case a broader and participatory level of community engagement was brought to bear on the process of death and dying. <http://guilfordjournals.com/doi/abs/10.1521/jsyt.2013.32.1.56>

Cont.

Noted in Media Watch, 20 May 2013:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE* | Online – Accessed 19 May 2013 – '**Considering the role of social work in palliative care: Reflections from the literature.**' Since the essence of all social work practice entails matters of loss and adjustment to changes in a person's assumptive world ... social workers are ... particularly well placed to provide skilled psychosocial support of all kinds to those struggling to come to terms with terminal illness. <http://oro.open.ac.uk/37581/1/Considering%20the%20role%20of%20social%20work%20in%20EJPC%20PDF.pdf>

Noted in Media Watch, 23 July 2012:

- *COMMUNITY CARE* | Online – 19 July 2012 – '**Social work "too often missing from end-of-life care."**' Social workers have a vital role in end-of-life care but they often struggle to perform it because of cuts, workloads and a lack of confidence, says a report from the National End of Life Care Programme.¹ <http://www.communitycare.co.uk/Articles/19/07/2012/118394/Social-work-39too-often-missing-from-end-of-life.htm>

1. 'The route to success in end of life care – achieving quality for social work,' National End of Life Care Programme, The College of Social Work & National Health Service, July 2012. http://www.endoflifecareforadults.nhs.uk/assets/downloads/EoLC_Social_Work_Route_to_Success_web.pdf

End of life care in Canada: A report from the Canadian Academy of Health Sciences Forum

CLINICAL & INVESTIGATIVE MEDICINE, 2013;36(3):E112-E113. The Canadian Academy of Health Sciences held a forum entitled, 'End of Life Care: the Last 100 Days' ... highlighting recent research, current controversies, and future directions to improve end-of-life care in Canada. Three articles in this issue of *Clinical Investigative Medicine* build on presentations from that day. <http://cimonline.ca/index.php/cim/article/view/19720>

N.B. Journal contents page: <http://cimonline.ca/index.php/cim/issue/current>

Preferred place of death

Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers

THE COCHRANE LIBRARY (Cochrane Pain, Palliative & Supportive Care Group) | Online – 6 June 2013 – When faced with the prospect of dying with an advanced illness, the majority of people prefer to die at home, yet in many countries around the world they are most likely to die in hospital. The authors reviewed all known studies that evaluated home palliative care services, i.e., experienced home care teams of health professionals specialised in the control of a wide range of problems associated with advanced illness – physical, psychological, social, spiritual. They wanted to see how much of a difference these services make to people's chances of dying at home, but also to other important aspects for patients towards the end of life, such as symptoms (e.g., pain) and family distress. The authors also compared the impact on the costs with care. On the basis of 23 studies ... they found that when someone with an advanced illness gets home palliative care, their chances of dying at home more than double. Home palliative care services also help reduce the symptom burden people may experience as a result of advanced illness, without increasing grief for family caregivers after the patient dies. In these circumstances, patients who wish to die at home should be offered home palliative care. There is still scope to improve home palliative care services and increase the benefits for patients and families without raising costs. <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD007760.pub2/abstract>

Cont.

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 4 June 2013 – '**Place of death, and its relation with underlying cause of death, in Parkinson's disease, motor neurone disease, and multiple sclerosis: A population-based study.**' In this study, 125,242 patients with Parkinson's disease, 23,501 with multiple sclerosis, and 27,030 with motor neurone disease were included. Home deaths ranged from 9.7% (Parkinson's disease) to 27.1% (motor neurone disease), hospice deaths ranged from 0.6% (Parkinson's disease) to 11.2% (motor neurone disease) and hospital deaths ranged from 43.4% (Parkinson's disease) to 55.8% (multiple sclerosis). <http://pmj.sagepub.com/content/early/2013/06/03/0269216313490436.abstract>

N.B. Several articles on preferred place of death are noted in Media Watch, 3 June 2013 (pp.12-13).

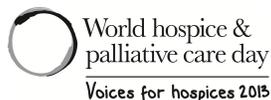
End-of-life care in Italy

Improving the quality of life of terminally ill oncological patients: The example of palliative care at Hospice Villa Speranza

FUTURE ONCOLOGY, 2013;9(6):771-776. Hospice Villa Speranza (HVS) is a National Health System-accredited facility of the Università Cattolica del Sacro Cuore (Rome), which has been providing palliative care for patients since 2000, both as hospice and home care. The assistance supplied by HVS is in line with national and international guidelines on palliative care and it is enriched by a constant interaction with the Hospital Policlinico A Gemelli (Rome), a leading center for healthcare in Italy. Unlike other hospices present in Italy, HVS is an academic hospice, whose services are strictly interconnected with the activities of University Hospital A Gemelli and other healthcare structures. An example of the results achieved thanks to the connection between HSV and the Hospital Policlinico A Gemelli is the creation of the Palliative Simultaneous Care model, which is dedicated to patients who require palliative care and focuses on starting the treatment as early as possible when needed. <http://www.futuremedicine.com/doi/pdf/10.2217/fo.13.59>

Least said, soonest mended?: Responses of primary school teachers to the perceived support needs of bereaved children

JOURNAL OF EARLY CHILDHOOD RESEARCH, 2013;11(2):95-107. Every 22 minutes in the U.K., a child is bereaved of a parent, making up some 24,000 a year. An even greater number experience the loss of a grandparent. There is a limited, but growing, body of research into the impact of grief and bereavement on young children and how their support needs might be met. This article expands upon research with primary school teachers articulating something of their knowledge and experience in encountering bereaved children. The discussion elucidates teachers' confidence – or reluctance – in broaching the topic, highlighting the lack of specific training within teacher education for understanding and supporting bereaved children. Compassionate understanding is offered to some children, but many others detect a wall of silence, which, when encountered in early childhood, can have detrimental consequences for their personal, social and academic development. The article calls for policy and practice that will ameliorate this situation. <http://ecr.sagepub.com/content/11/2/95>



<http://www.worldday.org/>

12 October 2015

Withholding and withdrawal of "futile" life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand

JOURNAL OF LAW & MEDICINE | In print – Accessed 4 June 2013 – This article examines the law in Australia and New Zealand that governs the withholding and withdrawal of "futile" life-sustaining treatment. Although doctors have both civil and criminal law duties to treat patients, those general duties do not require the provision of treatment that is deemed to be futile. This is either because futile treatment is not in a patient's best interests or because stopping such treatment does not breach the criminal law. This means, in the absence of a duty to treat, doctors may unilaterally withdraw or withhold treatment that is futile; consent is not required. The article then examines whether this general position has been altered by statute. It considers a range of suggested possible legislation but concludes it is likely that only Queensland's adult guardianship legislation imposes a requirement to obtain consent to withhold or withdraw such treatment. <http://eprints.qut.edu.au/60506/2/60506.pdf>

Noted in Media Watch, 9 August 2010:

- THOMSON REUTERS AUSTRALIA | Online – 4 August 2010 – **'Withholding and withdrawing life-sustaining medical treatment.'** At common law, a competent adult can refuse life-sustaining medical treatment, either contemporaneously or through an advance directive which will operate at a later time when the adult's capacity is lost. Legislation in most Australian jurisdictions also provides for a competent adult to complete an advance directive that refuses life-sustaining medical treatment. <http://eprints.qut.edu.au/33686/>

Palliative care training gains ground in Middle Eastern countries

JOURNAL OF PALLIATIVE CARE MEDICINE | Online – Accessed 6 June 2013 – The responses and observations gleaned from two ASCOMECC [American Society of Clinical/Middle East Cancer Consortium] workshops in the Middle East ... provide further support for the notion that additional efforts are needed to improve the management of cancer-related physical and emotional symptoms by means of ongoing training sessions for all care givers, in particular physicians and nurses, as has been recently advocated. Thus, more work is needed, perhaps in medical and nursing schools, but certainly in residency and fellowship programs. Oncologists can help patients understand their condition by giving personalized information. Truthful conversations that acknowledge death help patients understand their curability. Oncologists, however, need help in breaking bad news. Additionally, in most Middle Eastern countries, physicians learn only about opiates' side effects, not their potential benefits and modern principles of pain relief. Significantly, palliative care still is not taught to medical students in 80% of the world. Hence, one of the key challenges in the Middle East is developing human capacity and training. It is recommended that palliative care education and training begin as early as possible in graduate school, although it is not too late for practicing health care professionals to pursue this specific training within their areas of interest. <http://www.omicsgroup.org/journals/2165-7386/2165-7386-S3-e001.pdf>

Noted in Media Watch, 11 April 2011:

- *JOURNAL OF PEDIATRIC HEMATOLOGY/ONCOLOGY*, 2011;30(Suppl.1). **'Palliative care in Middle-Eastern countries.'** The focus of this article is on palliative care in Cyprus, Egypt, Israel, Pakistan, the Palestinian Authority and Turkey. Other articles focus on opioid use in pain management. Contents page: <http://journals.lww.com/jpho-online/toc/2011/04001>

End-of-life care in the Republic of Korea

Public perception and acceptance of the National Strategy for Well-Dying

KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE, 2013;16(2):90-97. Ten years have passed since the government announced its plan to institutionally support hospice and palliative care. The authors conducted a survey on people's perception and acceptance of well-dying. The most important factor for well-dying was placing no burden of care on others (36.7%) and the second most important factor was staying with their family and loved ones (19.1%). Among nine suggestions of policy support for well-dying, the most popular was the promotion of voluntary care sharing (88.3%), followed by the palliative care training support for healthcare providers (83.7%) and the support for palliative care facilities instead of funeral halls (81.7%). The idea of formulating a five-year national plan for end-of-life care drew strong support (91%). According to the survey, the plan should be implemented by the central government (47.5%), the National Assembly (20.2%) or civic groups (10%). This study demonstrated the public consensus and their consistent direction toward policy support for well-dying. Results of this may serve as a foundation for the establishment of policy support for people's well-dying and palliative care at the national-level. <http://www.koreamed.org/SearchBasic.php?RID=0155KJHPC/2013.16.2.90&DT=1>

Noted in Media Watch, 7 January 2013:

- *JOURNAL OF THE KOREAN MEDICAL ASSOCIATION*, 2012;55(12):1171-1177. '**Current status of end-of-life care in Korean hospitals.**' The level of end-of-life (EOL) care quality in the Republic of Korea has been regarded as inferior to more advanced countries. The EOL care delivered has varied depending on physicians' perceptions and patients' family requests for care. <http://synapse.koreamed.org/DOLx.php?id=10.5124/jkma.2012.55.12.1171>

Moral distress in end-of-life care: Promoting ethical standards of executive nursing practice

NURSE LEADER, 2013;11(3):51-54. Providing end-of-life care to dying individuals has the potential to be morally distressing to patients, families, and care providers when disagreements around the ethical nature of care arise. Advances in life-sustaining medical technologies, coupled with an increase in the aging population in an era where healthcare resources are limited, have contributed to the urgency of this issue in nursing executive practice. In order to effectively mediate an ethically sound resolution that is supportive of patient-centered care and sensitive to the needs of the healthcare team, nursing leaders need to have a working knowledge of underlying ethical principles and professional duties. This article presents an analysis of the moral distress in relation to end-of-life care in contemporary nursing practice. A case study is used to illustrate key concepts. A proposed plan of action based on current evidence is presented that is intended for use by the nurse executive. <http://www.sciencedirect.com/science/article/pii/S1541461213000256>

Trajectory of parental hope when a child has difficult-to-treat cancer: A prospective qualitative study

PSYCHO-ONCOLOGY | Online – 5 June 2013 – Two overarching categories defining hope as a positive inner source were found [in this prospective and longitudinal study] across time, but their frequency varied depending on how well the child was doing and disease progression: future-oriented hope and present-oriented hope. Under future-oriented hope, the authors identified the following: hope for a cure and treatment success, hope for the child's future, hope for a miracle, and hope for more quality time with child. Under present-oriented hope, they identified hope for day-to-day/moment-to-moment, hope for no pain and suffering, and hope for no complications. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3305/abstract>

N.B. Several articles on hope are noted in Media Watch, 22 April 2013 (pp.12-13).

Cont.

Of related interest:

- *PEDIATRIC BLOOD & CANCER* | Online – 3 June 2013 – '**Racial and ethnic differences in hospice enrollment among children with cancer.**' Results of this study indicate that race/ethnicity and diagnosis are likely to play a role in hospice enrollment during childhood. A striking number of patients of all race/ethnicities left hospice prior to death. <http://onlinelibrary.wiley.com/doi/10.1002/pbc.24590/abstract>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BRITISH MEDICAL JOURNAL* | Online – 30 May 2013 – '**Dutch doctors to receive more clarity over use of advance euthanasia directives for patients with dementia.**' Senior figures in Dutch medicine and politics are set to decide whether advanced euthanasia directives can, in practice, replace verbal requests if patients with dementia are no longer able to express their wishes. Doctors in the Netherlands have expressed "difficulties" with this "grey area," arguing that some communication is essential if they are to understand properly their patients' suffering and wishes. But eminent figures in medical ethics argue that doctors are placing themselves above the 2002 euthanasia law. <http://www.bmj.com/content/346/bmj.f3545>

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[Media Watch Online](#)

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpcconnection.ca/newsletter/inthenews.html>

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

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.palliativecareconsultation.ca/?q=mediawatch>

Europe

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

International

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> (Scroll down to 'Aggregators' and Barry Ashpole and Media Watch)

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 6 June 2013 – '**Palliative sedation versus euthanasia: An ethical assessment.**' The aim of this article was to review the ethical debate concerning palliative sedation. Although recent guidelines articulate the differences between palliative sedation and euthanasia, the ethical controversies remain. The dominant view is that euthanasia and palliative sedation are morally distinct practices. However, ambiguous moral experiences and considerable practice variation call this view into question. The increasing interest in palliative sedation may reemphasize characteristics of health care that initially encouraged the emergence of palliative care in the first place: the focus on therapy rather than care, the physical dimension rather than the whole person, the individual rather than the community, and the primacy of intervention rather than receptiveness and presence. [http://www.jpmsjournal.com/article/S0885-3924\(13\)00235-2/abstract](http://www.jpmsjournal.com/article/S0885-3924(13)00235-2/abstract)

Worth Repeating

Trajectories of disability in the last year of life

NEW ENGLAND JOURNAL OF MEDICINE, 2010;362(13):1173-1180. According to the hypothesis of a compression of morbidity, if the onset of disability could be postponed, then lifetime disability could be compressed into a shorter average period before death. Supporting this hypothesis, data from several large national surveys have shown a decline in disability rates that exceeds the observed decline in mortality. Although informative at the population level, these results may not be directly relevant to individual patients, their families, or their physicians, who may be more interested in knowing the likelihood and course of disability at the end of life. Previous research has shown the majority of older persons are disabled in the last year of life. Much less is known, however, about the trajectories of disability at the end of life. The authors conducted a study to identify clinically distinct trajectories of disability in the last year of life and to determine whether and how the distribution of these trajectories differs according to the condition leading to death. The authors postulated that for each condition there would

be considerable heterogeneity in the disability trajectories at the end of life. To accomplish their objectives, they used data from a longitudinal study that included monthly assessments of disability for more than 10 years in a large cohort of older persons. <http://www.nejm.org/doi/full/10.1056/NEJMoa0909087#t=articleDiscussion>

Extract from the *New England Journal of Medicine* article

Results suggest that the need for services at the end of life to assist with essential activities of daily living is at least as great for older persons dying from organ failure and frailty as for those dying from a more traditional terminal condition such as cancer, and that the need is much greater for older persons dying from advanced dementia. Nonetheless, the absence of a predictable disability trajectory based on the condition leading to death for most decedents poses challenges for the proper allocation of resources to care for older persons at the end of life.

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