Media Watch...

is intended as an advocacy, research and teaching 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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Compilation of Media Watch 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

The language and terminology of end-of-life care: 'Palliative care: From oncology to all nursing arenas – good practice or scaring the patients?' (p.12), in *Maturitas.*

Canada

Watchdog cautions doctors in Sunnybrook end-of-life case

ONTARIO | The Toronto Star - 17 June 2015 - After twice exonerating two Sunnybrook [Health Sciences Centre] doctors for their conduct in a controversial 2008 end-oflife case, Ontario's medical watchdog has had what experts are calling an unprecedented change of heart. The College of Physicians & Surgeons has issued written cautions against Drs. Martin Chapman and Donald Livingstone after previously rejecting a formal complaint and two appeals by the daughter of a man they treated. "Dr. Chapman and Dr. Livingstone's conduct was not completely appropriate, and some action is necessary," reads the latest ruling by the college's Inquiries, Complaints & Reports committee, obtained by the Star. "This complaint has focused their attention on the need to educate themselves and to consider how they might handle a similar situation differently in the future." Joy Wawrzyniak filed the complaint and appeals against the two physicians after the death of her father, Douglas DeGuerre, at Sunnybrook on 22 September 2008. The 88-year-old man had wanted to be given every chance at life with a "full code" designation on his chart,

Wawrzyniak says. That wish was ignored when physicians unilaterally changed his status to "do not resuscitate" just hours before he entered into cardiac arrest. Medical staff looked on as she called out for their help to save him, Wawrzyniak alleged in a 2009 complaint to the college and in a \$1 million civil suit against Chapman and Livingstone. "In our view, Drs. Chapman and Livingstone failed to properly communicate with Ms. Wawrzyniak ... when they made the decision that it was appropriate in the circumstances to change her father's status," reads the college committee's latest ruling. http://www.thestar.com/news/gta/2015/06/18 /watchdog-cautions-doctors-in-sunnybrookend-of-life-case.html

Specialist Publications

'Last rights: *Cuthbertson v. Rasouli* – What the Supreme Court didn't say about end-oflife treatment decisions' (p.10), in *Health Law in Canada*.

What have governments done to prepare for the aging population problem?

THE NATIONAL POST | Online – 15 June 2015 – Consider that over the next several decades, Canada's population will go through a shift of epic proportions due to our nation's aging population. Note that in 2010, there were 4.9 people working for every retiree in the country. By 2030, that ratio is expected to shrink to a mere 2.7 workers per retiree. Every province in the country will face this challenge and it will put tremendous pressure on government revenues and expenditures. As the percentage of retired people in Canada increases, governments will face a revenue squeeze. This is due to the fact that people who are working tend to earn more money and pay more in taxes than senior citizens getting by on fixed incomes. Whether we're talking income taxes, sales taxes, gas taxes or other government fees, working people are a cash cow for governments. That's not a criticism of senior citizens; it's just a fact of life. http://news.nationalpost.com/full-comment/colin-craig-what-have-governments-done-to-prepare-for-the-aging-population-problem

Of related interest:

iPOLITIC | Online – 16 June 2015 – 'Health-care leaders' debate identifies priorities for reform.' As an exercise in identifying priority areas for reform and investment, the [recent] Great Canadian Healthcare Debate was unquestionably a resounding success. As an actual debate, though, it pretty much fizzled, if only because there was a remarkable degree of consensus at the National Health Leadership Forum ... around systemic needs within Canadian health care. http://ipolitics.ca/2015/06/16/health-care-leaders-debate-identifies-priorities-for-reform/

N.B. Delegates were asked to vote on a broad range of issues to determine priorities for Canada's health care system. Motions that "failed to make the cut," however, included ones that directly addressed some of the major priorities identified by Canadians in a recent HealthCare-CAN-commissioned poll, e.g., that 90% want more done on palliative care.¹ Source: *iPOLITIC* <u>http://ipolitics.ca/2015/06/15/great-canadian-healthcare-debate-tackling-systemic-priorities/</u>.

In a new Ipsos Reid survey for HealthCare*CAN*, 90% of respondents say the health care system needs more support and resources to make patients as comfortable as possible at the end of life. Sources: http://www.healthcarecan.ca/woeful-palliative-care-system/ and http://www.ipsos-na.com/news-polls/pressrelease.aspx?id=6888

Waterloo-Wellington Local Health Integrated Network struggles to get patients to where they want to die

ONTARIO | *The Cambridge Times* – 14 June 2015 – People continue to die while waiting for support or beds in residential hospice and palliative care to open up. A priority of the Waterloo Wellington Local Health Integrated Network (LHIN) is to improve end-of-life care and ensure patients can die where they choose. But according to its most recent Health System Improvement Dashboard, there's a high risk the LHIN won't meet its target of getting people back home with the appropriate supports or into the community setting desired. In that priority area, the local LHIN is currently ranked 10th out of 14 in Ontario. The province set a target of a 10% decrease for all of the LHINs. Currently, St. Mary's General Hospital has seen a more than 11% increase in patients waiting for beds or community supports, while Grand River Hospital has seen a 0.7% decrease. According to a 2015 Ontario Hospital Association report, 9.7% of all bed types in the Waterloo Wellington LHIN were used for patients awaiting an alternate level of care in the third quarter of the 2014-2015 fiscal year.¹ That would include those waiting for residential hospice and palliative care beds. It's also costly. Dying in hospital costs about \$900 a day compared to about \$450 in hospice. http://www.cambridgetimes.ca/news-story/5675844-waterloo-wellington-lhin-struggles-to-get-patients-to-where-they-want-to-die/

 'Alternate Level of Care,' Access to Care, for the Ontario Hospital Association (Cancer Care Ontario), April 2015. <u>https://www.oha.com/CurrentIssues/Issues/Documents/ALC%20Report%20-%20April%202015.pdf</u> **N.B.** Two reports published in 2014 "comment" on the provision and delivery of end-of-life care in Ontario: 1) 'Health Care for People Approaching the End of Life: An Evidentiary Framework,' Health Quality Ontario (Ontario Health Technology Advisory Committee), published in *Ontario Health Technology Assessment Series*, 2014;14(14):1-45¹ [Noted in Media Watch, 22 December 2014, #389 (p.3)] ...and, 2) '2014 Report of the Office of the Auditor General of Ontario,' (Chapter 3: Ministry of Health & Long Term Care – Palliative Care, pp.258-288)² [Noted in Media Watch, 15 December 2014, #388 (p.2)]

- 1. http://www.hqontario.ca/Portals/0/Documents/eds/synthesis-report-eol-1412-en.pdf
- 2. http://www.auditor.on.ca/en/reports 2014 en.htm

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE GLOBE & MAIL | Online 16 June 2015 'Tories will likely seek assisted-death dead-line extension, says MacKay.' Setting the stage for a confrontation with the Supreme Court, Justice Minister Peter MacKay says the Conservative government, if re-elected in October, would ask the court to extend its deadline for legalizing physician-assisted death, citing time constraints caused by the upcoming election. Mr. MacKay said the government wants to ensure that vulnerable people, such as those with Alzheimer's disease, are protected from having pressure put on them to seek death when they do not want to do so. In effect, without new criminal laws, assisted death would be in a legal sense similar to abortion a decision made between patient and doctor. Mr. MacKay said it would be "dangerous and irresponsible" to allow such a legal void. He said the election in October will take at least four, and arguably six, months from the legislative process. http://www.theglobeandmail.com/news/national/tories-will-likely-seek-assisted-death-deadline-extension-says-mackay/article24991897/
- BRITISH COLUMBIA | CBC News 14 June 2015 'How Margot Bentley is complicating the right-to-die debate.' Margot Bentley has no idea what she unleashed. Dying with Dignity, a 30-year-old organization dedicated to expanding end-of-life options, is reporting "goodbye" letters that say, "I don't want to end up like Margot Bentley." "People are angry with us" says Wanda Morris, the organization's CEO." They say we told them advance-care directives about dying are followed these days." Not for Margot Bentley. Bentley, 83, a retired nurse who looked after patients with dementia, wrote what she called her "statement of wishes" in 1991. That statement appeared clear to her and her family, but a judge did not see it that way. Bentley's case demonstrates just how complicated advance-care directives are. She authorized her husband and daughter to make medical decisions on her behalf "if I reach the point when I cannot recognize my family." She wrote, "I direct that I be allowed to die," and she specified no heart resuscitation, no surgery, no breathing intervention and "no nourishment or liquids." Bentley was diagnosed with Alzheimer's disease 16 years ago. Now she languishes in a semivegetative state in a care home run by Fraser Health, the regional health care authority in Abbotsford, B.C. She is unresponsive in every way but one: She continues to eat when prodded with a spoon. Fraser Health refused to follow her directive, when Bentley's family asked it to do so. Katherine Hammond, her daughter and also a nurse, asked as an alternative to take her mother home and with the help of palliative care nurses allow her mother to die at home. The response from Fraser Health was to put a "police order" on Margot Bentley's chart. Abbotsford police were to be called if Hammond or her stepfather attempted to remove Bentley. http://www.cbc.ca/news/health/how-margot-bentley-is-complicating-the-right-to-die-debate-1.3107703

Noted in Media Watch, 9 March 2015, #400 (p.2):

 BRITISH COLUMBIA | The Province (Vancouver) – 3 March 2015 – 'Family of Alzheimer's patient loses right-to-die case despite living will.' The B.C. Court of Appeal dismissed a bid from the family of an Alzheimer's patient who argued she is being kept alive in a care home against her will. Justice Mary Newbury said in a ruling 83-year-old Margaret Bentley is exercising her consent when she opens her mouth to accept food and water. http://www.theprovince.com/Family+Alzheimer+patient+loses+right+case+despite+living+wi ll/10858017/story.html

<u>U.S.A.</u>

Physician Orders for Life-Sustaining Treatment (POLST)

Oregon Health & Science University starts online system for end-of-life care instructions

OREGON | *The Washington Times* – 16 June 2015 – An end-of-life medical order developed in Oregon is moving online to ensure that patients receive the kind of care they want when the time comes. Oregon Health & Science University has launched a digital system for Physician Orders for Life-Sustaining Treatment (POLST). Physicians fill out orders electronically and enter them into the state's registry with a keyboard click. The old system, which involved lots of scribbling, faxing and scanning of pink sheets of paper and then typing them into the registry, was prone to error. The POLST system has spread to 43 states; each has its own system or is developing one. Each registry is independent. In Oregon, the registry is housed at OHSU, but not part of the hospital.http://www.washingtontimes.com/news/2 015/jun/16/ohsu-starts-online-system-forend-of-life-care-ins/

Specialist Publications

[•]Reflections on the graying of America: Implications of Physician Orders for Life-Sustaining Treatment' (p.15), in *Rutgers Journal of Law & Public Policy.*

A new way for family caregivers to get lawmakers' attention

FORBES | Online – 15 June 2015 – Here is a political mystery: At least 44 million Americans are caring for aging parents or other relatives and friends. That's more than one of every six adults in the U.S. – an enormous voting block. Yet, their interests are largely ignored both in Washington and in state capitals. Now, the Altarum Institute, a non-partisan, Washington-based research organization, has come up with a new way to get caregiver issues on the political radar. The initiative. called the Family Caregiver Platform Project, is aimed at getting families who help their loved ones with personal care involved in writing the policy platforms of the political parties. By themselves, these platforms don't matter much anymore. More often than not, presidential candidates ignore their party's issue statements, which generally reflect the views of their most committed, but most ideologically extreme, base. State party platforms get even less attention. However, Altarum may be on to something. The process of drafting these policy statements is often the one time when politicians, party officials, activists, and ordinary citizens get together in a room to discuss issues. It is an opportunity for family caregivers to raise concerns that are often ignored by lawmakers (at least until they have had first-hand experience caring for a family member of their own), http://www.forbes.com/sites/howardgleckman/2015/06/15/a-new-way-for-familycaregivers-to-get-lawmakers-attention/



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a 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 college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://www.ipcrc.net/barry-r-ashpole.php

Prison release rarely an option for dying state inmates

PENNSYLVANIA | Daily Local News (West Chester) - 14 June 2015 - Leon Jesse James was supposed to die in prison. As a convicted murderer, Pennsylvania gave him no possibility of parole, meaning he'd spend nearly his entire adult life incarcerated for a 1971 fatal shooting... Barely 18 at the time, he was angry and immature. Over four decades, his family watched him grow up and then grow old in prisons... The anger faded, but its consequences remained, leaving little hope that he'd ever return home. Strangely, that changed when he could no longer walk. "He couldn't even tie his own shoes," said his sister Anna Garrity, describing his rapid deterioration last year from pancreatic cancer. Cancer meant his mandatory life term was nearly over. But losing his mobility made him a potential candidate to live his final days outside prison, and, with a judge's blessing, he became one of only nine inmates since 2010 to be granted a compassionate release from the ... state prison system. Reform advocates say Pennsylvania's law is so strict that compassionate releases almost never happen, even when inmates qualify. The burden almost always rests on families to petition for release, not prison staff who see daily evidence of an inmate's decline. <u>http://www.dailylocal.com/generalnews/20150614/prison-release-rarely-anoption-for-dying-state-inmates</u>

Prison Hospice Backgrounder

The provision – or lack – of quality end-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of the articles, reports, etc., noted in the weekly report is available on the Palliative Care Community Network website at: <u>http://www.pcne.com/community/pg/file/read/3389844/end-oflife-care-in-prisons</u>

Fighting for control of hospice dollars in Tri-Counties

CALIFORNIA | *Pacific Coast Business Times* – 12 June 2015 – Medicare began paying hospices in 1983 for patients who have given up aggressive treatment and whom doctors only give six months, or less, to live. While the original idea behind hospice care was to reduce expensive endof-life, hospital intensive treatment, hospice-related Medicare costs have been steadily increasing. Medicare spending for hospice care rose by more than 400% from \$2.9 billion in 2000 to \$15.1 billion in 2012, according to the Medicare Payment Advisory Commission (MedPAC), a Medicare watchdog group Congress created. What began as a spiritually motivated movement has transformed into an industry dominated by for-profit firms. In 1990, only 5% of hospices were for-profit. By 2013, they made up 66% of all hospice providers, according to the National Hospice & Palliative Care Organization. For-profit hospices generally have a bigger profit margin than nonprofits, according to MedPAC. The aggregate profit margins, which don't account for bereavement services or volunteer work, were 15.4% for the for-profit hospices nationwide in 2012 and 3.7% for non-profits, MedPac states. <u>http://www.pacbiztimes.com/2015/06/12/fighting-for-controlof-hospice-dollars-in-tri-counties/</u>

N.B. Selected articles on for-profit and non-profit hospice agencies listed in past issues of Media Watch are noted in the weekly report of 8 June 2015, #413 (pp.4-5).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

THE NEW YORKER | Online – 22 June 2015 – 'The death treatment.' The right-to-die movement has gained momentum at a time of anxiety about the graying of the population; people who are older than sixty-five represent the fastest-growing demographic in the United States, Canada, and much of Europe. But the laws seem to be motivated less by the desires of the elderly than by the concerns of a younger generation, whose members derive comfort from the knowledge that they can control the end of their lives. Diane Meier, a professor of geriatrics at

Cont.

Mount Sinai School of Medicine, in New York, and one of the leading palliative-care physicians in the country, told me that "the movement to legalize assisted suicide is driven by the "worried well," by people who are terrified of the unknown and want to take back control." She added, "That is not to say that the medical profession doesn't do a horrible job of protecting people from preventable suffering." Like most doctors who specialize in palliative care, a field focussed on quality of life for patients with severe and terminal illnesses, she thinks legalizing assisted suicide is unnecessary. "The notion that if people don't kill themselves they're going to die on a ventilator in the hospital would be humorous if it weren't so serious," she said. She believes that the angst propelling the movement would be diminished if patients had greater access to palliative care and if doctors were more attentive to their patients' psychological suffering. http://www.newyorker.com/magazine/2015/06/22/the-death-treatment

 MAINE | Bangor Daily News – 15 June 2015 – 'Maine Senate rejects right-to-die bill in razorthin vote.' The concept of allowing terminally ill patients to end their own lives under a doctor's supervision hit a roadblock when the Senate voted 18-17 against it. The bill would allow physician-assisted suicide, but only with a range of caveats, including that the patient has to take lethal drugs by his or her own hand after significant counselling from health care professionals. https://bangordailynews.com/2015/06/15/politics/state-house/maine-senate-rejects-right-to-diebill-in-razor-thin-vote/

International

Watchdog outlines serious failings by National Health Service trusts

U.K. (England) | The Telegraph - 17 June 2015 - A catalogue of serious failings by National Health Service (NHS) trusts across the country have been outlined in a damning report by the health service ombudsman.¹ A litany of complaints made by patients and their families .. highlight poor complaint handling and failures across the NHS. The report ... contains the details of 163 investigations into unresolved complaints made over two months last year... The ombudsman said of 618 complaints made during October and November 2014, 41% were upheld. http://www.telegraph.co.uk/news/11678966/ Watchdog-outlines-serious-failings-by-NHStrusts.html

Extract from Parliamentary & Health Service Ombudsman report

Trust staff left Ms. G's family outside a cubicle for five hours. The family could hear their mother's last hours and her eventual death, but they were not allowed to see her until 45 minutes after she had died. <u>http://www.ombudsman.org.uk/make-acomplaint/case-summary-</u> article?runnum keyword=524

N.B. The Ombudsman only sees those cases it has not been possible to resolve locally. However, its casework adds insight into what goes wrong in the most complex cases and what learning there might be for the NHS to prevent similar situations occurring again.

 'Report on selected summaries of investigations by the Parliamentary & Health Service Ombudsman: October to November 2014,' Parliamentary & Health Service Ombudsman, 2015. <u>http://www.ombudsman.org.uk/ data/assets/pdf file/0008/31697/Selected-summaries-ofinvestigations-by-PHSO-October-to-November-2014.pdf</u>

Noted in Media Watch, 25 May 2015, #411 (p.6):

U.K. (England) | Parliamentary & Health Service Ombudsman – 19 May 2015 – 'Dying without dignity.' The NHS needs to get better at: 1) Recognising people are dying; 2) Making sure symptoms are properly controlled; and, 3) Communicating with people, families and each other. http://www.ombudsman.org.uk/ data/assets/pdf file/0019/32167/Dying without dignity report ...pdf

Cont.

Of related interest:

U.K. (England) | BBC News – 17 June 2015 – 'Elderly "being trapped" in hospital, says Age UK.' Age UK ... analysis shows patients spent a total of nearly 2.5 million days stuck in a hospital over the past five years. There is a crisis in social care ranging from a shortage of care home places to a lack of district nurses to help people in their own home. It says the situation has got worse and the number of people being kept in hospital in 2014-15 increased by 19% on the previous year. http://www.bbc.com/news/health-33154093

End-of-life care in Australia

The slow politics of dignity for the aged and dying in Australia

AUSTRALIA | *The Conversation* – 15 June 2015 – The contrast between rights with dignity and rights without is increasingly apparent with regard to two groups of Australians who are much in the news lately. These are those who have retired from the full-time workforce and those who are in the last stage of their lives – whether in their own homes or in some form of assisted-living accommodation. The dignity aspect is present for most of those in the first group, which now contains a hefty percentage of the so-called baby boomer generation. Their rights to an adequate retirement income and access to necessary medical care are widely recognised and embraced by a great majority of the population. This extends to these matters increasingly at the centre of a vote-bidding war between the various political parties. But there is precious little dignity for those in the second group. This already contains nearly all the parents of the first group and will soon contain its own older members as well. https://theconversation.com/the-slow-politics-of-dignity-for-the-aged-and-dying-in-australia-43169

Of related interest:

- AUSTRALIAN AGEING AGENDA | Online 17 June 2015 'National palliative care training for regional, rural services.' Some 900 rural and regional health, aged and community care workers nationally will be the initial target of cutting-edge training being developed to support the psychological needs of terminally ill people, their families and caregivers. The capacity-building program, which is being developed and delivered by regional and rural community care aged provider and training organisation integrated living Australia, will also be made available online and embedded in vocational education and university courses to target other existing and future workers. http://www.australianageingagenda.com.au/2015/06/17/national-palliative-care-training-for-regional-rural-services/
- AUSTRALIA (South Australia) | ABC News 15 June 2015 'Palliative care services slashed in south east.' The Palliative Care Council of SA says terminally ill patients in the south east deserve better following Country Health SA's announcement they will cut palliative care positions in the region. As of 1 July, palliative nursing staff will be halved, bereavement services for Mount Gambier & Naracoorte will go, and a head of palliative care position will also be cut. http://www.abc.net.au/local/stories/2015/06/15/4254883.htm?site=southeastsa

End-of-life care in Mexico

Breakthrough for pain treatment

MEXICO | Human Rights Watch – 15 June 2015 – Mexico's introduction ... of a new system for prescribing and dispensing strong prescription pain medicines will significantly improve health care for people with advanced illnesses... Estimates by the World Health Organization and the Worldwide Hospice & Palliative Care Alliance suggest more than half of the 600,000 people who die every year in Mexico require palliative care, frequently including treatment of significant pain. The new system allows physicians to download from a secure website special prescriptions with bar codes required for prescribing opioid pain killers. It also introduces electronic record keeping

for pharmacies. Until now, physicians had to travel in person to state capitals to obtain bar code stickers, a highly time-consuming requirement that discouraged many physicians from prescribing these medicines. Pharmacies had to record all transactions involving these medicines in multiple log books, a significant bureaucratic burden. <u>http://www.hrw.org/news/2015/06/15/mexico-breakthrough-pain-treatment</u>

Noted in Media Watch, 15 December 2014, #388 (p.6):

- MEXICO | Human Rights Watch 10 December 2014 'Important advance in care for incurably ill.' The government has released long-awaited guidelines to its healthcare system that will operationalize provisions on end-of-life care as outlined in Mexico's 2009 health law. In October, Human Rights Watch highlighted ... the barriers faced by tens of thousands of patients who suffer unnecessarily from severe pain and other symptoms.¹ Although the Health Ministry was supposed to issue the guidance within six months of the 2009 law coming into effect, it was held up for years, delaying the effect of the law. <u>http://www.hrw.org/news/2014/12/10/mexicoimportant-advance-care-incurably-ill</u>
 - 'Care When There Is No Cure: Ensuring the right to palliative care in Mexico,' Human Rights Watch, 28 October 2014. [Noted in Media Watch, 3 November 2014, #382 (p.7)] <u>http://www.hrw.org/reports/2014/10/28/care-when-there-no-cure</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | Dutch News 19 June 2015 'Children should be allowed to opt for euthanasia: doctors.' Children who are suffering serious pain and have no prospect of improvement should be allowed to request euthanasia, whatever their age, according to the Dutch association for child medicine. The association was asked to draw up its standpoint on child euthanasia by health minister Edith Schippers a year ago. The current age limit is a problem, doctors say, because younger children are also capable of understanding the consequences of their actions. <u>http://www.dutchnews.nl/news/archives/2015/06/children-should-be-allowed-toopt-for-euthanasia-doctors/</u>
- GERMANY | Deutsche Welle 17 June 2015 'How to die in Germany.' When a person's life draws to a close, they should be allowed to pass away with dignity and peace. This much, most everyone agrees on. But when it comes to the details of how people should be allowed to die, politicians, palliative care experts and church officials in Germany whole-heartedly disagree. The Bundestag discussed a new bill concerning palliative care that Health Minister Hermann Gröhe said would improve and expand the hospice and palliative care system in Germany, but that according to some experts could still use some improvements. Just an hour earlier, a group of Bundestag members introduced their own euthanasia bill, which goes a lot further than Gröhe's proposal too far, opponents, including doctors and church leaders, say. http://www.dw.de/how-to-die-in-germany/a-18522753
- FRANCE | Associated Press 16 June 2015 'France's Senate debates terminal sedation, not euthanasia.' France's debate over end-of-life care goes to the Senate, with a bill that would allow doctors to keep terminally ill patients sedated until death comes, but stops short of legalizing euthanasia and assisted suicide. Euthanasia is currently legal in The Netherlands, Belgium and Luxembourg, and recent polls show a large majority of French people favour legalization. But French lawmakers haven't been willing to go quite that far... The new bill would give people "the right to deep, continuous sedation until death." Some doctors say it can mean patients are sedated for weeks, and that euthanasia may be more humane. http://news.yahoo.com/frances-senate-debates-terminal-sedation-not-euthanasia-075935182.html

Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.18.

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

Indicators of integration of oncology and palliative care programs: An international consensus

ANNALS OF ONCOLOGY | Online – 18 June 2015 – Recently, the concept of integrating oncology and palliative care has gained wide professional and scientific support; however, a global consensus on what constitutes integration is unavailable. International experts ... rated a list of indicators on integration over three iterative rounds under five categories: 1) Clinical structure; 2) Processes; 3) Outcomes; 4) Education; and 5) Research. After three rounds of deliberation, the panellists reached consensus on 13 major and 30 minor indicators ... which may be used to identify centers with a high level of integration, and facilitate benchmarking, quality improvement and research. <u>http://annonc.oxfordjournals.org/content/early/2015/06/18/annonc.mdv269.abstract</u>

N.B. Selected articles on the integration of early palliative care with oncology care listed in past issue of Media Watch are noted in the issues of the weekly report of 30 March 2015, #403 (pp.15-16) and 22 December 2014, #389 (pp.14-15).

Of related interest:

- ANNALS OF PALLIATIVE MEDICINE | Online Accessed 19 June 2015 'Clinical oncology and palliative medicine as a combined specialty – a unique model in Hong Kong.' The importance of early integration of palliative care (PC) into oncology treatment is increasingly being recognized. However, there is no consensus on what is the optimal way of integration. This article describes a unique model in Hong Kong where clinical oncology and palliative medicine (PM) is integrated through the development of PM as a subspecialty under clinical oncology. http://www.amepc.org/apm/article/view/6257
- KLINICKÁ ONKOLOGIE: CASOPIS CESKÉ A SLOVENSKÉ, 2015;28(3):171-6. 'Early integration of palliative care into standard oncology care benefits, limitations, barriers and types of palliative care.' Early palliative care has been shown to provide benefits in quality of life, mood, symptoms, health care utilization and survival. In this review, the authors summarize published data about benefits and difficulties of early palliative care. They also discuss the model of general and specialized palliative care integrated into oncological practice, their differences and consequences. http://www.ncbi.nlm.nih.gov/pubmed/26062618
- THE LANCET ONCOLOGY | Online 18 June 2015 'Early in-patient palliative care consultation saves costs.' With an ageing population and expensive anticancer treatments becoming the standard of care, the cost of oncology care is increasing rapidly. However, a new study has shown early in-patient palliative care consultation with its focus on symptom management, psychosocial support, and advanced care planning has the added benefit of substantial cost savings for hospitals.¹ http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(15)00075-3/abstract
 - 'Prospective cohort study of hospital palliative care teams for inpatients with advanced cancer: Earlier consultation is associated with larger cost-saving...' *Journal of Clinical Oncology*, 8 June 2015. [Noted in Media Watch, 15 June 2015, #414 (p.5)] http://jco.ascopubs.org/content/early/2015/06/08/JCO.2014.60.2334.abstract?sid=8eeb2a9a -2c82-4c44-977e-20379484e230

The relationship between bereaved family caregivers and the hospital team in long term care: Cases of home condolence visits

GERONTOLOGY & GERIATRIC RESEARCH | Online – 30 April 2015 – Condolence visits are an integral part of the therapeutic medical process and contribute to the comprehensive treatment of the "whole" patient. This article describes the spontaneous evolvement of condolence visits by team members of an geriatric skilled nursing department and discusses the ensuing issues and

questions as a result. The recurring themes of the discussion were: Do these visits invade the privacy of the families during the initial mourning period? Are the home visits really a part of the professional treatment? Are these visits confusing the professional and personal boundaries? What purposes do these visits serve? Do these visits benefit the families and/or the staff? Given that the condolence visits are beneficial to team members and probably also to the bereaved family we discuss how should such visits be conducted? <u>http://omicsgroup.org/journals/the-relationship-between-bereaved-family-caregivers-and-the-hospital-team-inlong-term-care-cases-of-home-condolence-visits-2167-7182-1000210.pdf</u>

Of related interest:

- PALLIATIVE MEDICINE, 2015;29(7):574-576. 'Caregiving and bereavement research...' Investigation of phenomena associated with bereavement following sudden or untimely deaths figures prominently in the literature. This is hardly surprising: Not only has losing a loved one under traumatic conditions been established as a main risk factor for poor mental and physical health outcomes, but one type of complication following such deaths, namely, Post Traumatic Stress Disorder, has long been included as a mental disorder in the *Diagnostic & Statistical Manual of Mental Disorders*... Yet, there are features of bereavement following a period of illness in general and caregiving in particular which suggest the need for scientific attention to the consequences of this type of loss too. <u>http://pmj.sagepub.com/content/29/7/574.full.pdf+html</u>
- DEATH STUDIES | Online 18 June 2015 "'He's on his dying bed": Next-of-kin's experiences of the dying body.' For family members of dying patients grown accustomed to providing daily body care, the transition from home to hospital is stressful. We used the experiences surrounding death for 78 U.S. Veterans... This research is based on interviews conducted with decedent's next-of-kin. Themes of social disorganization and a loss of control over the body emerged.<u>http://www.tandfonline.com/doi/full/10.1080/07481187.2015.1056565#.VYQXb2dFCos</u>

Taking science seriously in the debate on death and organ transplantation

THE HASTINGS CENTRE REPORT | Online – 17 June 2015 – The concept of death and its relationship to organ transplantation continue to be a source of debate and confusion among academics, clinicians, and the public. Recently, an international group of scholars and clinicians, in collaboration with the World Health Organization, met in the first phase of an effort to develop international guidelines for determination of death. The goal of this first phase was to focus on the biology of death and the dying process while bracketing legal, ethical, cultural, and religious perspectives. The next phase of the project will include a broader group of stakeholders in the development of clinical practice guidelines and will use expert consensus on biomedical criteria for death from the first phase as scientific input into normative deliberation about appropriate policies and practices. <u>http://onlinelibrary.wiley.com/doi/10.1002/hast.459/abstract</u>

N.B. Selected articles on organ donation in the context of end-of-life care noted in past issues of Media Watch are listed in the issue of the weekly report of 23 March 2015, #402 (p.2).

Last rights: Cuthbertson v. Rasouli

What the Supreme Court didn't say about end-of-life treatment decisions

HEALTH LAW IN CANADA, 2015;35(4):106-119. In October 2010, Mr. Hassan Rasouli needed "routine" surgery to remove a benign tumour from his brain. As they say, the operation was a success, but things did go wrong. After surgery, Mr. Rasouli contracted meningitis, leaving his mental capacity severely compromised. The initial diagnosis was persistent vegetative state, but it was later "upgraded" to minimally conscious state. Fortunately for Mr. Rasouli and even though never discussed with him, his family knew to a certainty that he would want to continue life in that condition, even if it meant never leaving the Sunnybrook intensive care unit (ICU). Unfortunately

for Mr. Rasouli, the Sunnybrook intensive care physicians determined that further medical intervention would be futile. They advised his family they would be withdrawing life support unless his wife, who was his substitute decision-maker (SDM), obtained a court order preventing that. She did, in the Superior Court. The physicians appealed. The Court of Appeal dismissed their appeal. They appealed again. The Supreme Court of Canada also dismissed their appeal. Mr. Rasouli remains in a minimally conscious state in the Sunnybrook ICU. When the Supreme Court of Canada released its judgment in Cuthbertson v. Rasouli, dismissing the physicians' appeal, it was a relief to Mr. Rasouli's family but a disappointment to many. The judgment, while limited to the facts of this particular case, was not perceived to provide many guidelines for physicians as to how intractable end-of-life disputes could be resolved. It seemed the Supreme Court said that every time a substitute decision-maker insisted "everything be done" to continue the patient's life, the treatment team would either have to comply or make an application to court or (in Ontario) to the Consent & Capacity Board (CCB), challenging that demand. Some health practitioners wondered whether the judgment meant that they had to provide treatments they deemed futile, unethical, or in breach of the standard of care for as long as the patient's family demanded. In this article, the authors examine those conclusions, and offer suggestions for achieving ethical and legal treatment results that will help avoid the need for litigation, or if it cannot be avoided, facilitate better results for the patient as well as the substitute decision-maker and the treatment team - and meet the physicians' standard of care.

N.B. This article was co-authored by lawyer Mark Handelman, a former Vice Chair and Senior Lawyer Member of the Ontario Consent & Capacity Board and Dr. Michael Gordon, Medical Program Director of Palliative Care, Baycrest Geriatric Health Care System. To obtain a copy contact Mr. Handelman at: <u>m.handelman@sympatico.ca</u> [Co-author's e-mail given with permission]

Selected articles on the *Cuthbertson v. Rasouli* case listed in past issues of Media Watch are noted in the weekly report of 15 December 2014, #388 (pp.1-2).

Of related interest:

JOURNAL OF MEDICAL ETHICS | Online – 16 June 2015 – 'Patients, doctors and the good life (for the patient).'An earlier acceptance of the physician as the decision-maker at the bedside relied on the premise that, among those at the bedside, the physician was most likely to be a person of practical wisdom, what Aristotle called a phronimos (wisdom). The premise was that, in the welter of medical and non-medical considerations, the doctor was the most likely to pick out the best available option for the patient, the option that would best advance the patient's interests. Read this way, there are reasons for scepticism: in an era of hospital medicine, the doctor is unlikely to be sufficiently well acquainted with the patient to know what is best for her, what is in her best interests; if the decision is (non-medically) difficult, calling for sagacity and human insight, there is no reason to think that the doctor, through being selected, trained and put to work by the medical establishment, will have more of such qualities than the patient. It is thus understandable why the premise of physician wisdom might no longer seem attractive with decisionally competent patients. Turning to the surrogate context, three questions need answers: What did the patient say or indicate she wanted? What would the patient want? What is in the patient's best interests? http://jme.bmj.com/content/early/2015/06/16/medethics-2014-102505.extract

Media Watch posted on Palliative Care Network-e Website

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

Key concepts that people need to understand to assess claims about treatment effects

JOURNAL OF EVIDENCE BASED MEDICINE | Online – 11 June 2015 – People are confronted with claims about the effects of treatments and health policies daily. An initial list of concepts was generated by the project team by identifying key concepts in literature and tools written for the general public, journalists and health professionals, and consideration of concepts related to assessing the certainty of evidence for treatment effects. The authors invited key researchers, journalists, teachers and others with expertise in health literacy and teaching or communicating evidence-based health care to patients to act as the project's advisory group. The group provided feedback on the list of concepts, which includes 30 concepts divided into six groups: 1) Recognising the need for systematic reviews of fair tests; 2) Judging whether a test of treatments is fair; 3) Understanding the role of chance; 4) Considering all the relevant, reliable evidence; 5) Understanding the results of systematic reviews of fair tests: and, 6) Judging whether a systematic review of fair tests of a treatment is relevant. The concepts are considered to be universally relevant, and include considerations that can help people assess claims about the effects of treatments, including claims that are found in mass media reports, in advertisements and in personal communication. http://onlinelibrary.wiley.com/doi/10.1111/jebm.12160/abstract

Noted in Media Watch, 2 March 2015, #399 (p.8):

 JAMA INTERNAL MEDICINE | Online – 25 February 2015 – 'Challenges in Choosing Wisely's international future.' Since its 2012 launch by the American Board of Internal Medicine Foundation, the Choosing Wisely campaign has affected more than 60 U.S. specialty societies. The campaign is becoming an international phenomenon. This rapid expansion is a heartening sign that there is increasing international sentiment against wasteful medical practices. <u>http://archinte.jamanetwork.com/article.aspx?articleid=2130720</u>

Palliative care: From oncology to all nursing arenas – good practice or scaring the patients?

MATURITAS | Online – 11 June 2015 – The aim of this paper is to encourage critical discussion of an individual's understanding of palliative care and compare this with a health care professional's understanding of palliative care. In doing this, the paper serves to illustrate the importance of words attached to services – so with palliative care – are we providing good care, or scaring the patients? The paper touches on the historical origins of palliative care as an adjunct of oncology, to a specialism in its own right, and now as an integral part of all care – in a "generalist palliative care nurse." However, it is unlikely that patients and their families are aware of such developments and will see palliative care services as immediate end-of-life care. It is argued that whatever your thoughts on the use of the term "palliative care," it is important to understand what has resonance for patients. <u>http://www.sciencedirect.com/science/article/pii/S0378512215007021</u>

Selected articles on defining end-of-life care noted in past issues of Media Watch:

- U.K. | *The Guardian* 24 January 2014 "'Palliative" or "end of life"? Why it is important to say the right words.' In a recent study, responses to "What do you think and feel when you hear the terms "palliative" and "end-of-life" care?" included: "Palliative care means you're not getting better, doesn't it?"; "End-of-life care sounds a bit frightening"; "Palliative is gentler but more confusing," and "I've got no idea." [Noted in Media Watch, 3 February 2014, #343 (p.7)] http://www.theguardian.com/social-care-network/2014/jan/24/palliative-end-of-life-care-right-words
- THE ONCOLOGY REPORT | Online 10 April 2013 'Is the moniker "palliative care" too loaded?' A survey of 169 patients with advanced cancer found that those randomized to hear the term "supportive care" instead of "palliative care" rated their understanding, overall impressions and future perceived need for those services significantly higher. [Noted in Media Watch, 15 April 2013, #301 (pp.14-15)] <u>http://www.oncologypractice.com/oncologyreport/news/topnews/single-view/what-s-in-a-name-is-the-moniker-palliative-care-tooloaded/15b05715fc83fdc88503a88bc9cbfc0e.html
 </u>

Cont.

 SUPPORTIVE CARE IN CANCER | Online – 31 August 2012 – 'Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks.' Commonly used terms ... were rarely and inconsistently defined in the palliative oncology literature. [Noted in Media Watch, 3 September 2012, #269 (p.7)] <u>http://link.springer.com/article/10.1007/s00520-012-1564-y</u>

Avoiding hospitalisation at the end of life: Perspectives of general practitioners, nurses and family carers

NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE (Netherlands Medical Journal) | Online – 15 June 2015 – Interviews [with 26 GPs, 15 nurses and 18 family carers of 30 patients who had died non-suddenly] identified five key strategies that could help to avoid hospitalisation at the end of life: 1) Marking the approach of death and shifting the mindset regarding the care required; 2) Providing acute treatment and care at the end of life; 3) Anticipatory discussions and interventions; 4) Guiding and monitoring during the illness trajectory; and, 5) Continuity of care and treatment at home. It is necessary for these five strategies to be applied in an interrelated... http://translate.google.ca/translate?hl=en&sl=nl&u=https://www.ntvg.nl/&prev=search

N.B. Dutch language article. Selected articles on avoiding hospitalization at the end of life noted in past issues of Media Watch are listed in the issue of the weekly report of 16 March 2015, #401 (pp.11-12).

Unmet needs of caregivers of severely affected multiple sclerosis patients: A qualitative study

PALLIATIVE & SUPPORTIVE CARE | Online – 17 June 2015 – Multiple sclerosis (MS) patients' caregivers are sometimes considered as "hidden patients." How much more this might be true for caregivers of severely affected MS patients has so far been scarcely studied. Palliative care also addressing relatives' needs might therefore be very relevant for these caregivers. However, we do not yet know which unmet needs they have and how these could be met. Unmet needs were sorted into the following categories: "relationship to physician," "individual support by the health-care system," "relationship to the individual severely affected by MS," "end-of-life issues," "self-care," and "higher awareness of MS."

Cont. next page

Back Issues of Media Watch		
Image: Description of the service of the se	Contact Acknowledgements	Media Watch Archives • 2014, July - December • 2014, January - June • 2013, July - December • 2013, January - June • 2012, July - December • 2012, January - June • 2011, January - June • 2011, January - June • Current
CHEST Online – 5 March 2015 The tendency toward "either/or" thinking (either cure or comfort) in traditional biomedical care paradigms does title to optimize care in advancing chronic lithess. Calls for improved palliation in chronic lung disease mandate a review of related care gaps and current clinical practices. read more	2012, January - June 2011, July - December 2011, January - June Current	

recipients with their own and rarely focused on their own wishes and restrictions. A close patientcaregiver dyad makes it difficult to differentiate unmet caregiver needs. However, the palliative care approach might help caregivers of severely affected MS patients by answering questions on disease progress and end-of-life issues, as well as by offering respite care, support for self-care, and help in preserving one's identity, and also anticipating the time to come after the death. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9786858&fulltextType =RA&fileId=S1478951515000607

Noted in Media Watch, 13 October 2014, #379 (p.16):

 PLOS ONE | Online – 6 October 2014 – 'Unmet needs of people with severe multiple sclerosis and their carers: Qualitative findings for a home-based intervention.' The Palliative Network for Severely Affected Adults with MS in Italy ... developed a home palliative care program for MS patients and carers, preceded by a literature review and qualitative study (here reported). <u>http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0109679</u>

An examination of the research priorities for a hospice service in New Zealand: A Delphi study

PALLIATIVE & SUPPORTIVE CARE | Online - 16 June 2015 - Open discussion of ideas has the potential to engage both staff and patients and carers in quality improvement initiatives, and to reinforce the value of research for patient care. At final ranking of six research themes encompassing twenty-three research topics were identified by staff and volunteers [i.e., the study participants]: 1) Symptom management; 2) Aged care; 3) Education; 4) Community; 5) Patient and family; and, 6) Bereavement support and young people. Patients and family carers agreed on four themes, made up of ten research topics: 1) Decision-making; 2) Bereavement and loss; 3) Symptom management: and. 4) Recognition of need and response of service. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9776379&fulltextType =RA&fileId=S1478951515000838

End-of-life care in Canada

Indigenous people's experiences at the end of life

PALLIATIVE & SUPPORTIVE CARE | Online – 15 June 2015 – Eighteen studies met the criteria for inclusion in this study. "Preparing the spirit" for transition to the next life was the overarching theme ... [which] ... occurred within the context of "where we come from." Processes involved ... were healing, connecting, and protecting; through these processes, "what I want at the end of life" was realized. The studies identified barriers within healthcare systems and current healthcare provider practices to "preparing the spirit." Findings provide a beginning understanding of the end-of-life experiences of indigenous peoples and a foundation for future research. More interpretive qualitative research is critical if palliative care services. the healthcare system, and healthcare providers are to reduce barriers to "preparing the spirit" for the journey at the end of life. http://journals.cambridge.org/action/displayA bstract?fromPage=online&aid=9776361&full textType=RA&fileId=S147895151500070X

Health Council of Canada 2013 report¹ extract

There is no funding for palliative/end-of-life care through the First Nations & Inuit Health Branch, and Health Canada's First Nations and Inuit Home & Community Care program is unable to provide 24-hour support for palliative clients and their families due to limited staffing and funds. Some research with seniors to define culturally appropriate end-of-life care yields a very different perspective from the Western model. In some Aboriginal cultures, death is part of life, and the care and comfort of heart and spirit take precedence over medical procedures and protocols.

1. 'Canada's Most Vulnerable: Improving Health Care for First Nations, Métis and Inuit Seniors,' Health Council of Canada (now defunct), November 2013. [Noted in Media Watch, 2 December 2013, #334 (pp. 1-2)] http://www.metisnation.org/media/422632/senior ab re port 2013 en final.pdf

Setting the facts straight on Wikipedia

POSTGRADUATE MEDICAL JOURNAL Online – 16 June 2015 – If you enter almost any name or topic into your search engine, the first item listed will probably be from Wikipedia. It has become, by default, the world's chief source of information. The quality of information you find there will of course be highly variable. As critics point out, anyone with access to a computer can edit a Wikipedia page. You can insert incorrect information, or add falsehoods out of malice, or as a prank. You can promote your own agenda, and repeatedly edit articles in the hope that your opponents will give up. You can do all of this anonymously. Schools and universities warn students to be extremely cautious about using Wikipedia, while journals discourage contributors from citing it. In spite of this, enthusiasts for Wikipedia point out that its accuracy has been demonstrated in a number of studies, including comparisons with Encyclopedia Britannica and the database of the U.S. National Cancer Institute. They argue that it allows continuous updating and improvement, in a way that conventional academic sources like journals cannot. Anyone who objects to its content, they suggest, can amend this instead of complaining, and test out whether the experience of doing so is really as negative as the critics suggest. http://pmj.bmj.com/content/early/2015/06/16/ postgradmedj-2015-133574.extract

What Wikipedia says about...

End-of-life care: <u>https://en.wikipedia.org/wiki/End-of-life_care</u>

Hospice: https://en.wikipedia.org/wiki/Hospice

Palliative care: https://en.wikipedia.org/wiki/Palliative_care

Noted in Media Watch, 2 June 2014, #360 (p.5):

- U.K. | BBC News 27 May 2014 'Trust your doctor, not Wikipedia, say scientists.' Wikipedia, the online encyclopaedia, contains errors in nine out of 10 of its health entries, and should be treated with caution.¹ Scientists in the U.S. compared entries about conditions such as heart disease, lung cancer [etc.] with peer-reviewed medical research. They said most articles in Wikipedia contained "many errors." <u>http://www.bbc.com/news/health-27586356</u>
 - 1. 'Wikipedia vs peer-reviewed medical literature for information about the 10 most costly medical conditions,' *Journal of the American Osteopathic Association*, 2014;114(5):368-373. http://www.jaoa.org/content/114/5/368.full

Noted in Media Watch, 8 August 2011, #213 (p.7):

JOURNAL OF ONCOLOGY PRACTICE | Online – 4 August 2011 – 'Patient-oriented cancer information on the Internet: A comparison of Wikipedia and a professionally maintained database.' Because of a lack of formal editorial control, the authors hypothesized that the content of Wikipedia would be less complete and accurate than that of a peer-reviewed web site. Although the Wikipedia resource had similar accuracy and depth as the professionally edited database, it was significantly less readable. http://iop.ascopubs.org/site/er/JOP000209.pdf

Reflections on the graying of America: Implications of Physician Orders for Life-Sustaining Treatment

RUTGERS JOURNAL OF LAW & PUBLIC POLICY, 2015;12(3):295-327. This article examines historical developments in advance directives, including their benefits and their problems, and discusses in detail the newest form of advance directive, the POLST form, or Physician Order for Life-Sustaining Treatment. Against the backdrop of the author's personal experience with advance directives, this article examines whether or not the newest "kid on the block" improves our

desire as a society to move towards more patient self-determination in end-of-life healthcare decisions, or whether it simply provides a clearer, less personal vehicle by which medical professionals can further avoid difficult discussions with patients and their surrogates when the end of life is near. This article concludes that although POLST forms may make treatment decisions easier for healthcare providers, there may be a disconnect between our laws approving such documentation and the reality of a patient's or patient's surrogate's own wishes at end-of-life. http://www.rutgerspolicyjournal.org/sites/rutgerspolicyjournal.org/files/issues/12_3/Jennison_FINA L.pdf

Selected articles on POLST noted in past issues of Media Watch:

- JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online 29 January 2015 'Use of the POLST program in the clinical setting: A systematic review of the literature.' Research suggests POLST is most commonly used in older, white patients near the end of life. Clinicians have generally positive attitudes regarding use of POLST yet report a wide range of challenges. POLST alters treatment in a way that is consistent with orders. However, evidence that POLST reflects patient or surrogate treatment preferences is lacking. [Noted in Media Watch, 2 February 2015, #395 (pp.9-10)] <u>http://onlinelibrary.wiley.com/doi/10.1111/jgs.13248/abstract</u>
- ANNALS OF EMERGENCY MEDICINE | Online 17 April 2014 'POLST and emergency medicine: Ethical considerations, legal issues, and emerging trends.' POLST is quickly growing in popularity and prevalence as a method of communicating the end-of-life care preferences for the seriously ill and frail nationwide. [Noted in Media Watch, 28 April 2014, #355 (p.10)] <u>http://www.annemergmed.com/article/S0196-0644(14)00220-0/abstract</u>
- THE LINACRE QUARTERLY, 2013;80(2):103-138. 'The POLST paradigm and form: Facts and analysis.' A critical analysis of the risks POLST poses to sound clinical and ethical decision-making with recommendations to help Catholic healthcare professionals and institutions address the challenges of end-of-life care. [Noted in Media Watch, 20 May 2013, #306 (p.13)] http://www.maneyonline.com/doi/abs/10.1179/0024363913Z.0000000027?queryID=33%2F29 1722

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.

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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.

End-of-life care in Japan

The effects of community-wide dissemination of information on perceptions of palliative care, knowledge about opioids, and sense of security among cancer patients, their families, and the general public

SUPPORTIVE CARE IN CANCER | Online – 16 June 2015 – Prejudices against palliative care are a potential barrier to quality end-of-life care. There have been few large-scale community-wide interventions to distribute appropriate information about palliative care, and no studies have investigated their impact on cancer patients, their families, and the general pub-



World hospice & palliative care day 10 October 2015

lic. The authors conducted a 3-year community intervention and evaluated the effects of distributing such information at the community level, and explored associations among levels of exposure, perceptions, knowledge, and the sense of security achieved. Their findings indicate that providing palliative care information via small media and lectures in the community is effective in improving perceptions of palliative care and knowledge about opioids among the community dwellers, especially for caregivers of the patients. The acquisition of adequate knowledge about palliative care from various information sources may improve people's sense of security regarding cancer. http://link.springer.com/article/10.1007/s00520-015-2788-4

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AMERICAN JOURNAL OF THE AMERICAN ACADEMY OF PSYCHIATRY & LAW, 2015;43(2): 183-190. 'Physician-assisted suicide: Considering the evidence, existential distress, and an emerging role for psychiatry.' Recent evidence regarding the implementation of assisted suicide (PAS) in the U.S. and The Netherlands is reviewed. Support is found for some concerns about PAS, such as the possibility mental illness occurs at higher rates in patients requesting PAS, but not for other concerns, such as the fear PAS will be practiced more frequently on vulnerable populations... These data and common arguments for and against PAS are discussed with an emphasis on the tension between values, such as maximizing patient autonomy and adhering to professional obligations, as well as the need for additional research that focuses more directly on the patient-centered perspective. Implications of the available evidence are discussed and lead to a consideration of mental anguish in terminally ill patients including aspects of existential distress and an acknowledgment of the importance of tailoring end-of-life care to the distinct set of values and experiences that shape each patient's perspective. The article concludes with a discussion of an expanding role for psychiatrists in evaluating patients who request PAS. <u>http://www.jaapl.org/content/43/2/183.abstract</u>
- SOUTH AFRICAN MEDICAL JOURNAL | Online Accessed 16 June 2015 'The Fabricius decision on the Stransham-Ford case¹ an enlightened step in the right direction.' Many diseases are associated with incredible pain and suffering. Others impair function and independence to the extent that human dignity is eroded. In many instances the natural history of such conditions often leads to death... In some cases, protracted ill health, pain, suffering and indignity ensue. Such circumstances have since time immemorial triggered the debate on euthanasia a debate on what it means to have a good death. Acting compassionately, many South African doctors have, to some extent, either passively or actively assisted patients in achieving a good death. http://www.hmpg.co.za/index.php/samj/article/view/7827
 - 'Right-to-die in South Africa: Assisted suicide advocate Robin Stransham-Ford dies before landmark court ruling on euthanasia,' *International Business News*, 30 April 2015. Euthanasia is illegal in South Africa, but Judge Hans Fabricius ruled a doctor could euthanize Stransham-Ford, terminally ill with prostate cancer, without legal or professional consequences. <u>http://www.ibtimes.com/right-die-south-africa-assisted-suicide-advocate-robin-stranshamford-dies-landmark-1903652</u>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <u>http://hospicecare.com/about-iahpc/newsletter/2015/06/media-watch/</u>

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

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

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

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: http://aphn.org/category/media-watch/

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <u>http://centres.sg/updates/international-palliative-care-resource-center-media-watch/</u>

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <u>http://palliativecarewa.asn.au/site/helpful-resources/</u>[Scroll down to 'International Websites' and <u>www.ipcrc.net/archive-global-palliative-care-news.php</u> to access the weekly report]

Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <u>http://hpcconnection.ca/general-resources/in-the-news/</u>

ONTARIO | Palliative Care Consultation Program (Oakville): <u>http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/</u> [Scroll down to 'Additional Resources']

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <u>http://www.eapcnet.eu/Themes/Organization/Links.aspx</u> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes

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

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