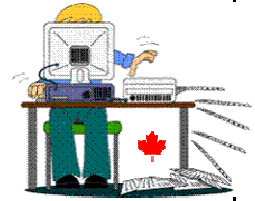


Media Watch...

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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Compiled & Annotated by Barry R. Ashpole

Breaking down barriers: Scroll down [Specialist Publications](#) and 'Enabling ICU patients to die at home' (p.14), in *Nursing Standards*.

Canada

Study: End-of-life care, 2012

STATISTICS CANADA | Online – 3 October 2014 – In 2012, 13% of Canadians (3.7 million) ... reported providing end-of-life or palliative care to a family member or friend at some point in their lives. Providing end-of-life care was most often a reality for those in their 50s and 60s. About one in five of these Canadians reported they had ever provided palliative care to a parent, spouse, grandparent, other family member or friend. As with caregiving overall, women were more likely than men to have provided assistance to someone who was terminally ill. Providing end-of-life care was sometimes done in the caregiver's own home. This was true for about one-third (35%) of Canadians who had provided care for their terminally ill relative or friend. Some caregivers felt they lacked the ... resources or abilities to provide

end-of-life care in their own home. Home care resources, financial assistance, paid time off from work and home modifications were among the supports listed by the one in six caregivers who would have preferred providing palliative care in their own home. <http://www.statcan.gc.ca/daily-quotidien/141003/dq141003c-eng.pdf>

Specialist Publications

'Excluding parental grief: A critical discourse analysis of bereavement accommodation in Canadian labour standards' (p.15), in *Work: A Journal of Prevention, Assessment & Rehabilitation*.

Of related interest:

- NEW BRUNSWICK | CBC News (Fredericton) – 2 October 2014 – '**Hospice in Chaleur region could save \$2-million a year, study suggests.**' Many patients end up spending their final days in hospital, at a cost of \$1,000 a day. "To provide that care in a hospice environment costs around \$445 to \$450 at a capacity of 160 annually, we're looking at over \$2 million in savings to the government's health care bill," said Sheraz Thomas, a researcher at the University of New Brunswick, who was commissioned by Chaleur Palliative earlier to study the issue. <http://www.cbc.ca/news/canada/new-brunswick/hospice-in-chaleur-region-could-save-2m-a-year-study-suggests-1.2785284>

Cont.

Noted in Media Watch, 15 September 2014, #375 (p.1):

- **NEW BRUNSWICK | Globe TV News (Moncton) – 12 September 2014 – 'Group urges equal access palliative care strategy for New Brunswick.'** The New Brunswick Hospice Palliative Care Association wants New Brunswick to adopt a provincial strategy for hospice palliative care that includes better training and pay for personal support workers, sustainable funding for residential hospices and equal access to this care across the province. <http://globalnews.ca/news/1558829/group-urges-equal-access-palliative-care-strategy-for-new-brunswick/>
- **THE GLOBE & MAIL | Online Commentary – 29 September 2014 – 'Why palliative care should come sooner than end-of-life.'** I often hear from the families of patients who are fighting an illness, such as cancer, wondering when the right time for palliative care is. Most people think of it later than is ideal, in fact, raising it only as a measure to be addressed towards the end of life. In contrast, there is now a movement towards ... "early palliative care" – getting help when it is needed, rather than waiting until all other treatments have been stopped. <http://www.theglobeandmail.com/life/health-and-fitness/health-advisor/why-palliative-care-should-come-sooner-than-end-of-life/article20828267/>

On palliative sedation

CBC Ottawa's Laurie Fagan wins health reporting award

CBC NEWS | Online – 30 September 2014 – The Canadian Medical Association has awarded CBC Ottawa journalist Laurie Fagan [the 2014 Excellence in Health Reporting on the radio] for her reporting on palliative sedation. The annual awards honour Canadian journalism focused on health, health professionals, and the health care system. Fagan produced an in-depth radio documentary, as well as radio and web stories, about the little-known, controversial therapy used at end of life for patients who have unbearable symptoms that can't be controlled by drugs. <http://www.cbc.ca/news/canada/ottawa/cbc-ottawa-s-laurie-fagan-wins-health-reporting-award-1.2782936>

Noted in Media Watch, 26 May 2014, #359 (p.1):

- **CBC RADIO | 'The Current' – 20 May 2014 – 'Palliative sedation: The new debate over end-of-life treatment in Canada.'** Palliative sedation is an end-of-life treatment that renders terminally-ill patients unconscious in the last stages of dying. It is used to alleviate excruciating pain, but some call it a form of "slow euthanasia," and say that it may even hasten death. <http://www.cbc.ca/thecurrent/episode/2014/05/20/palliative-sedation-the-new-debate-over-end-of-life-treatment-in-canada/>

Noted in Media Watch, 9 July 2012, #261 (p.12):

- **JOURNAL OF PALLIATIVE MEDICINE | Online – 2 July 2012 – 'Framework for Continuous Palliative Sedation Therapy in Canada.'** Canada does not have a standardized ethical and practice framework for continuous palliative sedation therapy. Canadian practice varies. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0498>

Caring for an aging population

THE NATIONAL | Online Commentary – 29 September 2014 – Cash-strapped provincial governments face a monumental challenge in the years ahead: Steeply increasing long-term care (LTC) costs, resulting from Canada's aging population. The surge in senior citizens in the coming years will bring rising demand for care to treat their frailties, whether mental, such as dementia, or physical, such as help with daily tasks. Trouble is, not enough Canadians are saving or insuring against future LTC risks, even though individuals, not governments, are responsible for the lion's share of the costs. <http://fullcomment.nationalpost.com/2014/09/29/blomqvist-busby-caring-for-an-aging-population/>

Cont.

Of related interest:

- *THE GLOBE & MAIL* | Online – 2 October 2014 – '**Why Canada's reliance on unpaid care is not sustainable.**' According to ... Statistics Canada ... 2.2 million individuals representing 8% of Canadians 15 years and older, received home care in 2012.¹ Most ... [1.8 million] ... consider that over a one-year period they received all the services they required ... to help with their daily activities. Only a minority, approximately 15%, said they had unmet home care needs. <http://www.theglobeandmail.com/globe-debate/why-canadas-reliance-on-unpaid-care-is-not-sustainable/article20888991/>
- 1. 'Canadians with unmet home care needs,' Statistics Canada, September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.3)] <http://www.statcan.gc.ca/pub/75-006-x/2014001/article/14042-eng.pdf>
- STATISTICS CANADA | Online – 26 September 2014 – '**Population aging is faster in Newfoundland and Labrador and slower in Saskatchewan.**' During the last 30 years, the proportion of seniors aged 65 years and older increased in all provinces and territories. The pace of population aging, however, was not uniform across Canada. <http://www.statcan.gc.ca/daily-quotidien/140926/dq140926b-eng.htm?HPA>

U.S.A.

Nine volunteers at Wabash Valley Correctional Facility provide hospice care for terminally ill offenders

INDIANA | *The Daily World* (Greene County) – 30 September 2014 – The Wabash Valley Correctional Facility (WVCF) is one of only 74 prisons across the U.S. participating in a hospice program for prisoners. The WVCF in Carlisle currently has a Compassionate Care Unit that is driven by volunteer offenders being housed at the facility. In order to participate in the program, the inmates are required to pass various screenings and background checks. Once admitted into the program, these volunteers participate in ongoing training that teaches them how to take care of terminally ill patients. When asked how the program has changed their outlook on life, the nine current volunteers at the WVCF all agreed that it has helped them in some way or another. "Some of us really are trying to change ourselves for the better and this program allows us to be the person no

one thought we could be," said one volunteer. "It makes us feel human again." <http://www.gcdailyworld.com/story/2123865.html>

Extract from *The Daily World* report

The Wabash Valley Correctional Facility (WVCF) welcomed Edgar Barends to present his "Prison Terminal: The Last Days of Private Jack Hall." The documentary is about a maximum-security hospice program at the Iowa State Penitentiary, where Barends filmed for six months. It was shown at the WVCF as a part of the film director's '50 Prisons in 100 Days Tour' to educate prisons around the country about hospice.

N.B. 'Prison Terminal: The Last Days of Private Jack Hall' website: <http://www.prisonterminal.com/index.html>

N.B. The provision and delivery of end-of-life care in the prison system have been highlighted in Media Watch on a regular basis. A compilation of articles, reports, etc., on this public health issue noted in the weekly report in recent years is available online at the Palliative Care Community Network website: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>.

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.16.

Dying without morphine

THE NEW YORK TIMES | Online – 30 September 2014 – The WHO has stated that access to pain treatment, including morphine, is an essential human right. Most suffering because of a lack of morphine is felt in the poorer regions of the globe. About 90% of the world's morphine consumption is in countries in North America and Europe, whereas all the globe's low- and middle-income countries combined use a mere 6%. In sub-Saharan Africa, which has the world's lowest consumption of morphine and other opioids, 32 of 53 countries have little, if any, access to morphine. However, this grossly lopsided use of morphine is not about the unequal distribution of wealth. Morphine is easy to produce and costs pennies per dose. But its per-dose profits are also low, which decreases a drug company's incentive to enter low-income markets in the developing world. If it were just about the money, the solution – subsidized access – would be obvious. However, the issue is complicated by a dizzying array of bureaucratic hurdles, cultural biases and the chilling effect of the international war on drugs, which can be traced back to the 1961 UN Single Conven-

tion on Narcotic Drugs that standardized international regulation of narcotics. <http://www.nytimes.com/2014/10/01/opinion/dying-without-morphine.html?hp&action=click&pgtype=Homepage&module=c-column-top-span-region®ion=c-column-top-span-region&WT.nav=c-column-top-span-region&r=0>

Extract from *The New York Times* article

India's narcotic regulatory agencies are so irrationally stringent that in 27 of the country's 28 states doctors simply avoid prescribing morphine for cancer pain for fear of running afoul of the law.

Specialist Publications

'Pain behind bars: The epidemiology of pain in older jail inmates in a county jail' (p.13), in *Journal of Palliative Medicine*.

N.B. Discussed at a recent UN General Assembly Special Session was the Commission on Narcotic Drugs historical emphasis on control of illicit drugs and the need, nonetheless, to improve availability of opioids for the relief of pain and suffering. Briefings can be accessed on the Commission's website at: http://www.unodc.org/ungass2016/en/cnd_intersessional_September.html. Scroll down to 'Ensuring the availability of controlled substances for pain medication.'

Noted in Media Watch, 25 August 2014, #372 (p.11):

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 19 August 2014 – '**An examination of global and regional opioid consumption trends 1980-2011.**' Great disparities in availability of opioids continue to exist between higher- and lower-to-middle-income countries. <http://informahealthcare.com/doi/abs/10.3109/15360288.2014.941132>

Noted in Media Watch, 3 February 2014, #343 (p.10):

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 28 January 2014 – '**The Global Opioid Policy Initiative: A wealth of information, but what is next?**' This study shows by country which opioid medicines are available, what they cost to the patient, and investigates the presence of barriers for access to these medicines. <http://informahealthcare.com/doi/abs/10.3109/15360288.2013.873513>

Noted in Media Watch, 27 January 2014, #342 (p.6):

- HUMAN RIGHTS WATCH | Online – 24 January 2014 – '**WHO boosts hope on pain relief, palliative care.**' World Health Organization has adopted a groundbreaking resolution urging countries to ensure access to pain medicines and palliative care for people with life-threatening illnesses. <http://www.hrw.org/news/2014/01/24/un-who-boosts-hope-pain-relief-palliative-care>

Is home health a solution to rising health costs?

U.S. NEWS & WORLD REPORT | Online – 30 September 2014 – Despite good news in recent weeks about the future of health care spending,¹ a daunting reality remains: The projections may turn out to be true for the next decade, but in the more-distant future, what can be done as Americans get older? Home health for seniors and people with disabilities can not only rein in costs, but can give people better health outcomes and the kind of care they want. The care options for home care are both social and medical, and can include medication reminders, family notifications, making appointments, arranging transportation and meal preparations. <http://www.usnews.com/news/articles/2014/09/30/is-home-health-a-solution-to-rising-health-costs>

1. 'What's behind the slowdown in health care costs,' *U.S. News & World Report*, 30 September 2014. The Congressional Budget Office, which provides nonpartisan budget and policy analysis to Congress, is predicting that Medicare spending will be \$95-billion lower by 2019 than it had predicted four years ago. <http://www.usnews.com/news/articles/2014/09/26/whats-behind-the-slowdown-in-health-care-costs>

Of related interest:

- NEW JERSEY | NJ.com – 30 September 2014 – '**New Jersey legislature approves bill requiring hospitals to teach family how to care for discharged patients.**' The legislation would let patients admitted to the hospital identify a caregiver who will be providing assistance when the patient is discharged. Within 24 hours after a decision is made to discharge a patient, the hospital would have to contact the caregiver and share a plan outlining what the patient needs in order to recover. Training via a live or recorded demonstration of the tasks involved, would be provided, as would an opportunity for the caregiver to ask questions. http://www.nj.com/politics/index.ssf/2014/09/nj_hospitals_would_have_to_teach_family_how_to_care_for_patient_after_hospital_discharge.html

End-of-life care needs concrete reforms, not sweeping rhetoric

MASSACHUSETTS | *The Boston Globe* – 28 September 2014 – How to obtain proper end-of-life care and die with dignity is a conversation topic that most patients and their doctors would prefer to postpone as long as possible. It is also a politically fraught issue, because any discussion of curbing expenditures on pricey treatments, even in hopeless cases, conjures up images of cold-hearted bean-counters... But treating high-intensity hospital care as the norm during the final stage of life isn't just hugely expensive; it also conflicts with what the overwhelming majority of patients actually wants. <http://www.bostonglobe.com/opinion/editorials/2014/09/27/dying-america-end-life-care-needs-concrete-reforms-not-sweeping-rhetoric/07idtEnnwhQAvloGb1hINN/story.html>

Noted in Media Watch, 21 October 2013, #328 (p.4):

- MASSACHUSETTS | *The Boston Globe* – 16 October 2013 – '**End-of-life rules proposed for Massachusetts health facilities.**' Health care-providers often fail to discuss end-of-life care preferences with patients, an omission Massachusetts regulators hope to change with proposed new rules that would require physicians and other staffers at hospitals, nursing homes, and health centers to provide information about choices for people near death. <http://www.boston.com/lifestyle/health/blogs/white-coat-notes/2013/10/16/end-life-rules-proposed-for-massachusetts-health-facilities/vU0leR49koQ2c3fVWARcbJ/blog.html>

Of related interest:

- *FORBES* | Online – 29 September 2014 – '**Who decides what medical care you receive at end of life?**' Who should decide what care you receive towards the end of your life — you or an "administrative tribunal" of "experts and wise community members"? If you want to retain control over your medical care, you must retain control over your medical dollars. He who pays the piper calls the tune. <http://www.forbes.com/sites/paulhsieh/2014/09/29/who-decides-what-medical-care-you-receive-at-end-of-life/>

Governor signs bill ... to relieve patient suffering

CALIFORNIA | *The Reporter* (Vacaville) – 27 September 2014 – Governor Edmund G. Brown, Jr., signed into law legislation ... expanding access to services to relieve suffering and enhance the quality of life of patients with cancer, dementia, cirrhosis and other serious illnesses – no matter their age or the stage of their illness. Senate Bill 1004 ... requires the Department of Health Care Services to establish standards and provide technical assistance to help Medi-Cal managed care plans provide palliative care services to patients of any age and stage of serious illness. http://www.thereporter.com/news/ci_26620171/governor-signs-bill-by-lois-wolk-relieve-patient

Noted in Media Watch, 12 May 2014, #357 (p.3):

- CALIFORNIA HEALTHLINE | Online – 8 May 2014 – '**Committee OKs bill to expand kids' palliative care pilot program to adults.**' The Senate Committee on Health unanimously approved a measure to expand a children's palliative care pilot program to the adult population of California. "This bill would direct the Department of Health Care Services to seek a waiver to evaluate a palliative care benefit in the Medi-Cal program," said Senator Ed Hernandez... <http://www.californiahealthline.org/capitol-desk/2014/5/committee-oks-bill-to-expand-kids-palliative-care-pilot-program-to-adults>

Assisted (or facilitated) death

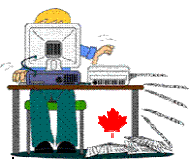
Representative sample of recent news media coverage:

- NEW JERSEY | *Asbury Park Press* (Neptune) – 27 September 2014 – '**Editorial: Offer choice, mercy to terminally ill.**' When a terminal illness has taken nearly everything from a person, including a future, that person should be able to hang onto at least one thing — the freedom to choose the manner, and to some extent, the time of his or her death. That's the purpose of the Aid in Dying for the Terminally Ill Act currently before the state Assembly. Supporters of the bill are working to get a vote on the bill sometime this fall. Both chambers of the Legislature should approve it and Governor Chris Christie should sign it. <http://www.app.com/story/opinion/editorials/2014/09/27/editorial-offer-choice-mercy-terminally/16289021/>

International

Does cancer get too much attention?

U.K. | BBC News – 3 October 2014 – Over recent years, new institutions, targets, campaigns, and funding have steadily helped drive improvements in cancer care, treatment and survival. However ... respiratory consultant Dr. Toby Maher of the British Lung Foundation argues that while efforts by the government, [the] National Health Service and other healthcare bodies to fight cancer are welcome, other diseases with similar rates of incidence and mortality should be given the same priority. <http://www.bbc.com/news/health-29363887>



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>

End-of-life care in Singapore

Home palliative care providers benefit from Ministry of Health's new funding model

SINGAPORE | Channel NewsAsia – 29 September 2014 – In July this year, the Ministry of Health (MOH) started funding home palliative care providers for every patient under their care on a monthly basis. Some providers have said they are receiving twice what they used to in funds since the new funding model kicked in. Home palliative care providers ... said this increased stream of funding has allowed them to launch new services, increase capacity, and be more flexible with resources. Previously, providers were reimbursed based on the number of visits. <http://www.channelnewsasia.com/news/singapore/home-palliative-care/1387910.html>

End-of-life care in Australia

Grattan Institute says plan your death, tell relatives how you want to die

AUSTRALIA | News.com.au – 28 September 2014 – Every 75 year old should sign a plan that tells doctors how they want to die, says a controversial report by a former health department chief.¹ Death has become over medicalised, institutionalised and stripped of its dignity with just one in seven of us fulfilling our wish to die at home surrounded by loved ones, the Grattan Institute report says. Part of the problem is a lack of government funding for palliative care that could help people die in their own homes. The report calls for \$237-million to be spent providing that care. Around 160,000 Australians die each year, but that number is expected to double in the next 25 years says former federal health department chief Stephen Duckett who co-wrote the report with health policy expert Hal Swiersson. Even though seventy per cent of people want to die at home, only about 14% do so, the report

says. Fifty-four per cent of us die in hospitals and 32% in residential care. In countries such as New Zealand, the U.S., Ireland and France around 30% of people die at home. <http://www.news.com.au/lifestyle/health/grattan-institute-says-plan-your-death-tell-relatives-how-you-want-to-die/story-fneuzlbd-1227073278870>

Extract from Grattan Institute report

Despite widespread assumptions about the cost of end-of-life care, only about \$5-billion a year is spent on the last year of life for older people in a health budget of \$100-billion. But only about \$100-million is spent on helping people to die at home. A change in focus will not save much, but will help more people to die well.

1. 'Dying Well,' Grattan Institute, September 2014. The Institute is an independent, public policy "think tank." Report: <http://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>

Of related interest:

- AUSTRALIA (New South Wales) | *Australian Ageing Agenda* – 30 September 2014 – '**In the place of their choice.**' As part of its four-year palliative care strategy, the New South Wales government is funding the state-wide roll-out of home-based palliative care packages to support more people to fulfil their wish to die at home. Funding has been provided for the roll-out of up to 2,863 home-based palliative care packages by 2015-2016. Most Australians say they want to be cared for and die at home. Yet across Australia only 16% of people achieve this outcome... <http://www.australianageingagenda.com.au/2014/09/30/place-choice/>

[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>

Elder care in the U.K.

Care ratings to target "shocking lack of respect"

U.K. (England) | *The Sunday Telegraph* – 28 September 2014 – A "shocking lack of respect for the elderly" is dragging down standards in care homes, the chief inspector of social care has warned. Andrea Sutcliffe said too many residents were forced to wear other people's clothes, left bruised by rough handling, and denied help eating and drinking, amid "truly awful" failings in care in some parts of England. As the Care Quality Commission prepares to introduce a new system of inspection, she told *The Sunday Telegraph* attitudes to the elderly needed to change to ensure pensioners were treated with dignity and kindness. The new regime,

which starts next week ... follows an overhaul of the inspectorate, which had been criticised for missing a string of scandals. <http://www.telegraph.co.uk/health/11126179/Care-ratings-to-target-shocking-lack-of-respect.html>

Specialist Publications

'The future funding of health and social care in England' (p.11), in *British Journal of General Practice*.

Noted in Media Watch, 21 July 2014, #367 (p.4):

- U.K. (England) | *The Guardian* – 16 July 2014 – '**Jeremy Hunt unveils new measures to tackle failing care homes.**' There are far too many failing care homes that people would not be happy to send their relatives to, the health secretary has said ... as he announced new measures to tackle failing care homes. <http://www.theguardian.com/society/2014/jul/16/jeremy-hunt-new-measures-tackle-failing-care-homes>

Of related interest:

- BBC NEWS | Online – 30 September 2014 – '**Global AgeWatch Index: Norway best for older people.**' Norway is the best place to grow old, according to an index of the quality of later life in 96 countries¹ ... [and] ... ranks Australia, Western Europe and North America highly, and Afghanistan last. Hot on the heels of Norway comes Sweden, closely followed by Switzerland, Canada and Germany. <http://www.bbc.com/news/world-29426285>

1. HelpAge International's Global AgeWatch Index: <http://www.helpage.org/global-agemwatch/>

- IRELAND | *The Irish Times* (Dublin) – 28 September 2014 – '**Neglect of elderly is "hidden euthanasia," Pope Francis says.**' Elderly people, including former Pope Benedict, attended a gathering of the wise and wrinkled at the Vatican today, where Pope Francis denounced the neglect and abandonment of the old as "hidden euthanasia." The pope sought to underscore the importance of the old in society and he said homes for the elderly could not be allowed to become "prisons" where care took a back seat to business interests by those who run them. According to the World Health Organization, there are 600 million people over 60 in the world today and the figure is expected to double over the next 11 years and reach two billion by 2050, most in the developing world. <https://www.irishtimes.com/news/world/europe/neglect-of-elderly-is-hidden-euthanasia-pope-francis-says-1.1944455>



Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | *NL Times* – 30 September 2014 – **'Nearly 5,000 chose euthanasia in 2013; 15% increase.'** Doctors in The Netherlands assisted 4,829 people to commit suicide in 2013, representing a 15% percent increase over 2012. The vast majority of cases involved patients suffering with cancer or unbearable pain, according to a report published by the five regional review committees. The report outlined how doctors working in 2013 performed the euthanasia procedure in almost all cases. The committee flagged doctors in five cases because they did not perform the procedure according to the guidelines. In two cases, doctors made mistakes in their methodology, prescribing a non-standard drug to make the patient comatose. In none of the five cases were the errors so severe that the Public Prosecutor had to be called in. Of the 4,829 people who were assisted, almost 3,600 were suffering from cancer related illnesses, 42 people reported having the procedure due to severe psychiatric problems, and 97 due to dementia cases where the patients were able to communicate their wish to die. Euthanasia has been legal in the Netherlands under strict conditions since 2002. <http://www.nltimes.nl/2014/09/30/nearly-5000-chose-euthanasia-2013-15-increase/>
- 1. Regionale toetsingscommissies euthanasia,' 29 September 2014. Dutch language edition: http://www.euthanasiecommissie.nl/Images/Persbericht%20RTE%20Jaarverslag%202013_tcm52-40694.pdf

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

Pediatric palliative care

Advance care planning: Practicalities, legalities, complexities and controversies

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 1 October 2014 – Paediatric Advance Care Planning provides a framework for paediatricians, families and their multidisciplinary teams to consider, reflect and record the outcome of their conversations about what might happen in the future in order to optimise quality of clinical care and inform decision-making. For some children and young people this will include discussions about the possibility of death in childhood. This may be unexpected and sudden, in the context of an otherwise active management plan or may be expected and necessitate discussions about the process of dying and attention to symptoms. Decision-making about appropriate levels of intervention must take place within a legal and ethical framework, recognising that the U.K. Equality Act (2010) protects the rights of disabled children and young people and infants and children of all ages to the same high quality healthcare as anyone else. <http://adc.bmj.com/content/early/2014/10/01/archdischild-2014-305945.abstract>

Of related interest:

- *JOURNAL OF PEDIATRIC NURSING* | Online – 28 September 2014 – **'Exploring the perceived met and unmet need of life-limited children, young people and families.'** This article presents a study ... which explored children and young people up to 25 years of age with life-threatening/limiting conditions and their families. Findings indicated that children and their families felt medical/nursing needs were well met but provision was needed for broader financial, social and emotional support alongside more responsive specialist therapies. <http://www.sciencedirect.com/science/article/pii/S0882596314002589>

The role and significance of nurses in managing transitions to palliative care: A qualitative study

BMJ OPEN | Online – 30 September 2014 – Nurses are generally present, and often influential, in supporting patient and family acceptance of medical futility and in assisting doctors in negotiating referral to palliative care. Yet the specificities of the nursing role and how nurses may contribute to timely and effective referrals is not well understood. This study aimed to systematically explore hospital-based nurses' accounts of the transition to palliative care, and the potential role of nurses in facilitating more effective palliative care transitions. Four significant themes emerged: 1) professional dynamics and the roles played by nurses in initiating the transition to palliative care; 2) the value of nurses' informal interactions in timely and effective transitions; 3) the emerging challenge of managing task-oriented nursing versus intense emotional nursing work at the point of medical futility; and, 4) the emotional burden experienced by nurses within this clinical context. <http://bmjopen.bmj.com/content/4/9/e006026.abstract?sid=e6e364a4-f32d-43bb-9e7e-28e212e20cf0>

Noted in Media Watch, 29 September 2014, #377 (p.11):

- *PALLIATIVE MEDICINE* | Online – 23 September 2014 – **'Breaking bad news about transitions to dying: A qualitative exploration of the role of the district nurse.'** While other colleagues can avoid breaking bad news of transition to dying, district nurses have no choice if they are to provide optimal end-of-life care. While ideally placed to carry out this work... <http://pmj.sagepub.com/content/early/2014/09/22/0269216314551813.abstract>

[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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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.

The future funding of health and social care in England

BRITISH JOURNAL OF GENERAL PRACTICE | Online – 1 October 2014 – These are embarrassing times for baby boomers. As beneficiaries of the [Clement] Attlee settlement, we have enjoyed affordable health care, decent housing, free higher education, and a generous welfare state. Notoriously, these are blessings that could be denied the next generation. The National Health Service is facing yet another funding crisis and social care is under increasing strain. The confusing border between the two has long been a source of administrative waste and frustration for users. Patterns of ill health, life expectancy, family structures, and medical technologies have changed considerably since 1948 when [economist William] Beveridge and [then Minister of Health Aneurin] Bevan established the current system. A King's Fund commission, chaired by the economist Kate Barker, proposes a new settlement fit for today's circumstances. An interim report used five criteria to assess future options: equity, transparency, efficiency, the split between collective and individual responsibility, and affordability. The evidence suggests that the present arrangements fail on all of these criteria. <http://bjgp.org/content/64/627/499>

Noted in Media Watch, 8 September 2014, #374 (p.3):

- COMMISSION ON THE FUTURE OF HEALTH & SOCIAL CARE IN ENGLAND | Online – 4 September 2014 – '**A new settlement for health and social care.**' The final report from the independent commission discusses the need for a new settlement for health and social care... <http://www.kingsfund.org.uk/publications/new-settlement-health-and-social-care>

Of related interest:

- *BRITISH JOURNAL OF SOCIAL WORK* | Online – 29 September 2014 – '**The fragmentation of social work and social care: Some ramifications and a critique.**' This paper critically appraises the impact of the fragmentation of social care and social work. In particular, it examines the impact of splintered services and roles upon employees, service users and carers. <http://bjsw.oxfordjournals.org/content/early/2014/09/28/bjsw.bcu088.abstract>

Does medical futility matter in "do not attempt CPR" decision-making?

INTERNATIONAL JOURNAL OF CLINICAL PRACTICE, 2014;68(10)1190-1192. The demographic trend towards an increasingly elderly population combined with advances in end of life care calls for a deeper understanding and common terminology about the concept of futility and additional influences on the resuscitation decision-making process. Such improved understanding ... and other contributing factors when making "do not attempt CPR" orders would help to ensure that clinicians make appropriate and thoughtful decisions on whether to recommend resuscitation in a patient. When estimating medical futility a physician should consider the chance of survival over different time periods and balance this against the chance of adverse outcomes. This information can then be offered to the patient ... so that the patient's views about what is acceptable for the survival chance, length and type of survival can be factored into the eventual decision. <http://onlinelibrary.wiley.com/doi/10.1111/ijcp.12476/abstract;jsessionid=30B30E748601D06EF6E36973779B51C9.f04t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

The strange allure of state "right-to-try" laws

JAMA INTERNAL MEDICINE | Online – 29 September 2014 – State "right-to-try" laws that purport to allow patients to be treated with unapproved drugs or devices seem likely to be futile. In May 2014, the governor of Colorado signed into law a so-called right-to-try bill; the intent of the law is to allow terminally ill patients to receive treatment outside of clinical trials with drugs and medical devices that the U.S. Food & Drug Administration (FDA) has not approved for marketing. <http://archinte.jamanetwork.com/article.aspx?articleid=1910562>

Cont.

Noted in Media Watch, 11 August 2014, #370 (p.4):

- ARIZONA | *The Washington Post* – 6 August 2014 – **“Right to try” measure to be considered in Arizona, other states.** Arizona could become the latest state to allow those who are terminally ill to try experimental treatment not yet approved by the Federal Drug Administration. <http://www.washingtonpost.com/blogs/govbeat/wp/2014/08/06/right-to-try-measure-to-be-considered-in-arizona-other-states/>

Noted in Media Watch, 30 June 2014, #364 (p.15):

- SCIENCE, 2014;344(6190):13229. **“Right to try” laws bypass Federal Drug Administration for last-ditch treatments.** Several state legislatures, prodded by desperately ill patients and a libertarian think tank, are defying federal regulators to make experimental drugs available to terminally ill patients outside of clinical trials. The new laws, called “Right to try,” went on the books in two states last month and are being considered in several others. <http://www.sciencemag.org/content/344/6190/1329.short>

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

Use of palliative care and hospice among surgical and medical specialties in the Veterans Health Administration

JAMA SURGERY | Online – 24 September 2014 – In the Veterans Health Administration population, surgical patients are less likely to receive either hospice or palliative care in the year prior to death compared with medical patients, yet surgical patients have a longer length of time in these services. Determining criteria for higher-risk medical and surgical patients may help with increasing the relative use of these services. Potential barriers and differences may exist among surgical and medical services that could impact the use of palliative care or hospice in the last year of life. <http://archsurg.jamanetwork.com/article.aspx?articleid=1906152>

The connection between evidence-based medicine and shared decision making

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2014;312(13):1295-1296. Evidence-based medicine (EBM) and shared decision making are both essential to quality health care, yet the interdependence between these two approaches is not generally appreciated. Evidence-based medicine should begin and end with the patient: after finding and appraising the evidence and integrating its inferences with their expertise, clinicians attempt a decision that reflects their patient's values and circumstances. Incorporating patient values, preferences, and circumstances is probably the most difficult and poorly mapped step – yet it receives the least attention. <http://jama.jamanetwork.com/article.aspx?articleid=1910118>

Noted in Media Watch, 28 July 2014, #368 (p.12):

- PATIENT EDUCATION & COUNSELING | Online – 21 July 2014 – **‘Understanding patient perceptions of shared decision making.’** There is no one-size-fits all process that leads patients to label a decision as shared. Rather, the outcome of “agreement” may be more important than the actual decision-making process for patients to label a decision as shared. [http://www.pec-journal.com/article/S0738-3991\(14\)00291-2/abstract](http://www.pec-journal.com/article/S0738-3991(14)00291-2/abstract)

Of related interest:

- JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2014;312(13):1342-1343. **‘Minimal clinically important difference: Defining what really matters to patients.’** When assessing the clinical utility of therapies intended to improve subjective outcomes, the amount of improvement that is important to patients must be determined. The smallest benefit of value to patients is called the minimal clinically important difference (MCID). The MCID is a patient-centered concept, capturing both the magnitude of the improvement and also the value patients place on the change. <http://jama.jamanetwork.com/article.aspx?articleid=1910090>

Cont.

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 2 October 2014 – '**Patients' priorities for treatment decision making during periods of incapacity: quantitative survey.**' Patients [i.e., study participants] endorsed three primary goals with respect to decision making during periods of incapacity: 1) being treated consistent with their own preferences; 2) minimizing the burden on their family; and, 3) involving their family in the decision-making process. However, no single goal was prioritized by a clear majority of patients. These findings suggest advance care planning should not be limited to documenting patients' treatment preferences. Clinicians should also discuss and document patients' priorities for how decisions are to be made. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9366424&fulltextType=RA&fileId=S1478951514001096>

Perhaps the subject of the questionnaire was too sensitive: Do we expect too much too soon?

JOURNAL OF HUNTINGTON'S DISEASE | Online – 25 September 2014 – Wishes for the end of life in Huntington's Disease – the perspective of physicians in 15 European countries. No abstract available. <http://iospress.metapress.com/content/j8126636q6375856/>

Noted in Media Watch, 24 December 2012, #285 (p.11):

- *JOURNAL OF MEDICAL ETHICS* | Online – 22 December 2012 – '**A plea for end-of-life discussions with patients suffering from Huntington's disease: The role of the physician.**' <http://jme.bmj.com/content/early/2012/12/21/medethics-2011-100369.abstract>

Pain behind bars: The epidemiology of pain in older jail inmates in a county jail

JOURNAL OF PALLIATIVE MEDICINE | Online – 29 September 2014 – The number of older jail inmates in poor health is increasing rapidly. Among older adults, pain is common and leads to greater acute care use. In jail, pain management is complicated by concerns about misuse and diversion. A lack of data about the prevalence and management of pain in older jail inmates limits our ability to develop optimal palliative care strategies for this population. [Study] participants' mean age was 59 years; 69% had multi-morbidity; 75% reported any pain; 39% reported severe frequent pain. Within a week of their interview, most participants with severe frequent pain had received an analgesic (87%) and many received an opioid (70%). High rates of pain in a rapidly growing population of older jail inmates with multi-morbidity and functional impairment suggest that jails are an important site for assessing symptom burden and developing appropriate palliative care interventions. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0160>

N.B. The provision and delivery of end-of-life care in the prison system have been highlighted in Media Watch on a regular basis. A compilation of articles, reports, etc., on this public health issue noted in the weekly report in recent years is available online at the Palliative Care Community Network website: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>.

Ethics and care for older people approaching the end of life – symptoms, choices and dilemmas

JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS OF EDINBURGH, 2014;44(3):238-239. Despite the recent controversies surrounding The Liverpool Care Pathway and challenges faced by those providing end-of-life care to older people there [has] emerged a strong consensus ... of the need to continue to strive for patient-centred coordinated care. Clinicians in both the hospital and community will be central to this as highlighted by the success of the 'Caring Together' initiative in Glasgow and anticipatory care planning in the Highlands. Excellent communication and teamwork underpin any successful initiative designed to provide high-quality care for older people approaching the end of life. <http://www.rcpe.ac.uk/sites/default/files/duncan.pdf>

Cont.

Of related interest:

- *JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS OF EDINBURGH*, 2014;44(3):214-215. **'The Liverpool Care Pathway: Benefit or harm?'** The Liverpool Care Pathway [LCP] was developed in the late 1990s ... and was rapidly promoted as a model of good practice. However, this rapid promotion occurred in the absence of strong evidence of benefits. What evidence there was came from quasi-experimental (non-randomised) studies, and audits that measured processes of care (e.g., whether opioids were prescribed), but not patient outcomes (e.g., whether patients' pain improved). This created a Catch-22 situation: once the LCP became accepted as a gold standard it was almost impossible to test it in a comparative study. <http://www.rcpe.ac.uk/sites/default/files/sleeman.pdf>

Grief & bereavement

Developing a support group for older lesbian and gay community members who have lost a partner

LGBT HEALTH | Online – 25 September 2014 – While bereavement support groups have been shown to be helpful in assisting older adults with spousal loss, many lesbian and gay older adults would not be comfortable in these groups. Lack of recognition of same sex relationships and fear of judgment are barriers that some older lesbian and gay people face when considering these services. In this report we discuss a community-university collaboration to develop a support group for the older lesbian and gay community in our area. The authors share lessons they learned in developing and conducting a group for older lesbian and gay adults experiencing partner loss. <http://online.liebertpub.com/doi/abs/10.1089/lgbt.2014.0039>

Of related interest:

- *DEATH STUDIES* | Online – 25 September 2014 – **'The economic cost of bereavement in Scotland.'** Spousal bereavement was associated with increased mortality and longer hospital stays, with additional annual cost of around £20-million. Cost of bereavement consultations in primary care was estimated at around £2-million annually. Bereaved people were less likely to be employed in the year of and two years after bereavement than non-bereaved matched controls. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2014.920435?queryID=%24%7Br esultBean.queryID%7D>
- *SCIENTIFIC STUDY OF LITERATURE*, 2014;4(1):68-88. **'Reading in times of loss: An exploration of the functions of literature during grief.'** Reading was most strongly associated with distraction and listening to music with recognition. Among 198 respondents, 64 reported using neither medium during their grief period, 65 used only music, 19 (10%) used only literature, and 50 used both. Using artistic media was related to an emotional experience of the loss in two ways: 1) preference for emotion-focused coping was greater among those who used artistic media; and, 2) those who had used artistic media also reported greater impact of the loss. <http://www.ingentaconnect.com/content/jbp/ssol/2014/00000004/00000001/art00005>

Enabling ICU patients to die at home

NURSING STANDARD | Online – 1 October 2014 – There is often an overlap between intensive care medicine and palliative medicine. When all curative treatment options have been explored, keeping the patient comfortable and free from pain is the main concern for healthcare practitioners. Patient autonomy in end of life decisions has not been encouraged in the intensive care unit (ICU), until now, because of its specialised and technical nature. Staff at the Royal Bolton Hospital [Lancashire, England] have broken down the barriers to enabling ICU patients to die in their own homes, and have developed a system of collaborative working that can help to fulfil a patient's final wish to go home. <http://rcnpublishing.com/doi/abs/10.7748/ns.29.5.46.e8971>

Bereavement and the workplace:

Excluding parental grief: A critical discourse analysis of bereavement accommodation in Canadian labour standards

WORK: A JOURNAL OF PREVENTION, ASSESSMENT & REHABILITATION | Online – 23 September 2014 – Universally, employment policies provide only for the practical issues of bereavement. Commonly, leave is three days, unpaid, and meant to enable ceremonial obligations. Policies do not acknowledge the long-term suffering caused by grief or the variable intensity of different kinds of loss. Managerial, moral, normative and neoliberal values embedded in these policies efface the intensely personal experience of grief, thereby leaving employees at risk for serious health and workplace safety issues. Bereavement leave currently understands grief as a generic, time-limited state with instrumental tasks and ceremonial obligations. In contrast, research characterizes responses to child loss as intense, highly personal experiences for which healing and recovery can take years. <http://iospress.metapress.com/content/y846mju257307701/>

Noted in Media Watch, 16 June 2014, #362 (p.1):

- CANADIAN HUMAN RIGHTS COMMISSION | Online – 11 June 2014 – **'Balancing work and caregiving obligations: New guide walks you through it.'** The Commission has released its *Guide to Balancing Work and Caregiving Obligations: Collaborative Approaches for a Supportive and Well-performing Workplace*. The guide offers employers and employees practical tips on what to do when an employee's family caregiving and work responsibilities come into conflict. http://www.chrc-ccdp.gc.ca/sites/default/files/a_guide_to_balancing_work.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BMC HEALTH SERVICES RESEARCH* | Online – 2 October 2014 – **'Cross-sectional research into counselling for non-physician assisted suicide: Who asks for it and what happens?'** The aim of this cross-sectional research was to obtain information about clients receiving counselling for non-physician assisted suicide, and the characteristics and outcome of the counselling itself. More than half of the clients were over 65 years old. More than one third of the clients had no wish to end life and 16% had an urgent wish to end life. Almost two thirds of the clients had not requested physician assistance in dying. Half of the clients had others involved in the counselling. More than half of the clients received explicit practical information concerning non-physician assisted suicide, while 13% of all clients actually ended their own life through non-physician assisted suicide. Clients without a (severe) disease were older than clients with a severe disease. They also had more problems of old age and existential suffering and more often wanted to be prepared for self-determination. The clients without a (severe) disease more often had no wish to end life and requested physician assistance in dying less often than clients with a severe disease. <http://www.biomedcentral.com/content/pdf/1472-6963-14-455.pdf>
- *JOURNAL OF FAMILY MEDICINE & PRIMARY CARE* (Academy of Family Physicians of India), 2014;3(3):230-237. **'Attitudes toward euthanasia and related issues among physicians and patients in a multi-cultural society of Malaysia.'** The majority of physicians and patients [i.e., survey respondents] did not support active euthanasia or physician-assisted suicide, no matter the circumstances... Both [were] opposed to its legalization... Both physicians (29.2%) and patients (61.5%) were in favor of withdrawing or withholding life-sustaining treatment to a patient with no chances of survival. <http://www.jfmpc.com/article.asp?issn=2249-4863;year=2014;volume=3;issue=3;page=230;epage=237;aulast=Rathor>
- *MEDSCAPE* (U.S.) | Online – 26 September 2014 – **'Special report: Physician-assisted dying – is resistance eroding?'** Access to the articles requires a subscription. Contents page: http://www.medscape.com/viewcollection/33226?nlid=66624_1842&src=wnl_edit_medp_wir&ac=213000DZ&spon=17

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/9/media-watch/>

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]

Asia

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

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

Australia

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

Canada

ALBERTA HOSPICE PALLIATIVE CARE ASSOCIATION: <http://ahpca.ca/> (Scroll down to 'Media Watch')

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

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

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

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [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: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

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