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

Following death: Scroll down to <u>Specialist Publications</u> and 'Updated guidance for professionals who provide care *after* death' (p.7), posted online by the National End-of-Life Care Programme and the National Nurse Consultant Group in the U.K.

Canada

More palliative care services needed in Manitoba, some help on way

MANITOBA | CBC Radio (Winnipeg) – 23 April 2015 – As the deadline for legislating assisted suicide approaches, health care experts in Manitoba are boosting services and the profile of palliative care. Jocelyn House ... is hoping to expand its facility, from four to 24 beds. "We are within days of presenting a proposal to the WRHA [Winnipeg Regional Health Authority] through a partnership with the Catholic Health Corporation," said Jackie Stephen, executive director of Jocelyn House. "We are hoping for a new 24-bed facility that Jocelyn House would operate. It could be a separate location, or we may expand this one as well." Jocelyn House has also launched a new website and Hospice & Palliative Care Manitoba rebranded with a new website earlier this year. The Canadian Virtual Hospice is a website designed and based in Winnipeg with international reach. The site helps people with concerns and questions about palliative care. Patients, family members and caregivers can ask a question and get a personal answer within a couple of days from a specialist. The site gets 10,000 hits a day, some from as far away as China and Australia. http://www.cbc.ca/news/canada/manitoba/more-palliative-care-services-needed-in-manitoba-some-help-on-way-1.3035738

Federal budget to boost Employment Insurance compassionate care leave

THE TORONTO STAR | Online – 21 April 2015 – The Conservatives will more than double [to 12 weeks] the amount of time Canadians can draw on employment insurance for compassionate leave to care for an ailing loved one... The benefit was first introduced in January 2004 and then expanded in 2006 by broadening the definition of family members who could access it. The benefit is meant to assist people forced to take time off work to act as a caregiver to a family member struggling with a grave illness. Previously, taking an extended leave from work meant the caregiver was financially penalized through the loss of income, not to mention putting his or her job in possible jeopardy. http://www.thestar.com/news/canada/2015/04/20/federal-budget-to-boost-eicompassionate-care-leave.html

Children's hospice in Ontario

Algoma Residential Community Hospice prepares for young patients

ONTARIO | The Sault Star (Sault Ste. Marie) – 19 April 2015 – The hospice where young Chiara Scornaiencki died is in Ottawa, not Sault Ste. Marie. Most end-of-life care facilities in Ontario, including Algoma Residential Community Hospice [ARCH], don't offer pediatric care. Less than 5% of the province's hospices have pediatric services, said Lee Skinner, fund development co-ordinator at ARCH. Services offered at the eight-bed Roger's House [in Ottawa] include end-of-life care for children and youth, pain management, and grief support. Limiting admission to patients 18 and up will soon change as the [Sault Ste. Marie] hospice is "weeks away from the implementation stages of a residential hospice pediatric care program."

Noted in Media Watch, 20 April 2015, #406 (p.13):

Staff would have to be trained and equipment, such as smaller beds for youngsters, purchased. That cost would have to be covered by ARCH, not the Ontario government. ARCH opened in 2008. Nearly 1,000 people will have died there by the end of this year. http://www.saultstar.com/2015/04/19/archprepares-for-young-patients

Specialist Publications

'The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase' (p.11), in *Health Psychology*.

PAEDIATRICS & CHILD HEALTH, 2015;20(3):153-154. 'Paediatric palliative care in Canada: A national survey of paediatricians.' Exposure to palliative care during residency training and continuing education would be beneficial to ensure paediatricians are aware palliative care is meant to offer the best possible quality of life for children with life-threatening conditions and their families... http://www.cpsp.cps.ca/uploads/publications/Highlights-paediatric-palliative-care.pdf



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 Resource Center website Care at: http://www.ipcrc.net/barry-r-ashpole.php

Communication with the Public, Politicians, and the News Media

by Barry R. Ashpole



In Section 6 (beginning p.357) of the 5th edition: <u>http://ukcatalogue.oup.com/product/academic/medicin</u> <u>e/clinical/palliative/9780199656097.do?sortby=bookTi</u> <u>tleAscend&thumbby=10&thumbby_crawl=10&zoneCo</u> <u>de=ACZC008#</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | The National Post 23 April 2015 'Confusion over euthanasia: Third of doctors wrongly believe it's family's call, Quebec poll finds.' A third of Quebec doctors and nurses believe legalized euthanasia would give them the right to end the life of an incompetent patient at a relative's request, according to a new survey that finds confusion over what is legal and what is not in end-of-life practices. Overall, 35% of respondents believed the use of lethal medication would be legal, when requested by a relative, under an assisted dying scheme despite the fact every Quebec government report since 2012 has made clear a voluntary request would have to come from the patient. Respondents seemed equally confused about what is already legal in Quebec. http://news.nationalpost.com/news/canada/confusion-over-euthanasia-third-of-doctors-wrongly-believe-its-familys-call-quebec-poll-finds
 - 'Health care professionals' comprehension of the legal status of end-of-life practices in Quebec: Study of clinical scenarios,' *Canadian Family Physician*, 2015;61(4):e196-e203. [Noted in Media Watch, 20 April 2015, #406 (p.2)] <u>http://www.cfp.ca/content/61/4/e196.full.pdf+html</u>
- ONTARIO | The Toronto Star 21 April 2015 'Nurses take the lead on assisted suicide.' Almost three months have passed since the Supreme Court handed down its historic decision to lift Canada's ban on assisted suicide. The court gave the federal government and the provinces one year to craft a new law that would balance the interests of patients seeking to end their lives, doctors unwilling to hasten death and individuals who need protection. It is a vital task. Without clear rules, doctors will have no criteria to apply when a patient seeks help to die; people with disabilities will have no legal safeguard and Canadians will have no opportunity to shape the laws that determine how they end their lives. Yet none of Canada's governments has taken up the Supreme Court's challenge. At the federal level, the Conservative cabinet has made it clear it sees no urgency. Liberal leader Justin Trudeau tried to initiate an all-party discussion, but his proposal that a special committee be struck to listen to Canadians, doctors and nurses, ethicists, lawyers, spiritual leaders and psycho-social specialists was defeated 146 to 132. No further deliberation is expected before October's election. The provinces - with the exception of Quebec, which passed its own assisted suicide law last summer - are looking to Ottawa for leadership. The Canadian Medical Association, likewise, is waiting for the federal government to act. It accepts that assisted suicide is a "therapeutic service." but wants explicit guidelines for its members. Rather than waiting for Canada's politicians and doctors to initiate a discussion of assisted suicide. Ontario's nurses have taken the lead. http://www.thestar.com/opinion/commentary/2015/04/21/nurses-take-the-lead-on-assistedsuicide-goar.html

N.B. The organization Dying with Dignity reports a federal government commission will embark on a six-month tour to probe views on assisted dying, according to *Le Devoir*.¹ Consultations will begin in June and wrap up in December. That means a three-to-four-member panel would report back to Parliament after the upcoming federal election. Justice Minister Peter MacKay wouldn't confirm the details of the consultation. However, he told *Le Devoir* news on the assisted dying file was imminent. The news suggests the federal government is responding to public calls to legislate new rules physician assisted dying in the wake of the Supreme Court's decision to decriminalize end-of-life choice. http://www.dyingwithdignity.ca/resources/blog_news/post/1383.php

- 'Une commission itinérante sur l'aide médicale à mourir, tranche le gouvernement fédéral,' Le Devoir (Montreal, Québec), 21 avril 2015. French language article. <u>http://www.ledevoir.com/politique/canada/437906/une-commission-itinerante-sur-l-aide-medicale-a-mourir-tranche-le-gouvernement-federal</u>
- MANITOBA | CBC News (Winnipeg) 20 April 2015 'Two prominent Manitoba doctors speak out against assisted suicide.' Two top doctors in Manitoba say physician assisted suicide is not the answer to addressing the suffering of dying patients. Both want to see more Canadians having access to comprehensive palliative care and more training for physicians. Too many people are dying badly in Canada ... said Dr. Harvey Chochinov, Canada's Research Chair in Palliative Care. Dr. Mike Harlos said the playing field isn't fair as the country moves towards physician assisted suicide. Harlos believes doctors who don't have adequate training in palliative care are more likely to seeing ending someone's life as the answer. And he's afraid patients may feel the same. http://www.cbc.ca/news/canada/manitoba/two-prominent-manitoba-doctors-speak-out-against-assisted-suicide-1.3022274

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

Is it time to make medical and family leave paid?

NATIONAL PUBLIC RADIO | Online - 22 April 2015 - It's been more than twenty years since passage of the landmark Family & Medical Leave Act, which allows workers to take up to 12 weeks of unpaid time off for medical or family reasons without losing their jobs. Some advocates and politicians say that it's time to plug a big hole in the law by requiring that workers get paid while they're on leave. But the change faces stiff opposition from some small business and other groups that argue it would be too expensive and an unnecessary government intrusion. Only 13% of workers [in the U.S.] had access to paid family leave in 2013, according to the Department of Labor's 2014 national compensation survey. Four states have implemented paid family leave programs; their experience may provide guidance for a national paid family leave law. http://www.npr.org/blogs/health/2015/04/22/ 401239857/is-it-time-to-make-medical-andfamily-leave-paid

Specialist Publications

'Public health imperative of the 21st Century: Innovations in palliative care systems, services, and supports to improve health and well-being of older Americans' (p.10), in *The Gerontologist.*

'Improving policies for caregiver respite services' (p.11), in *The Gerontologist*.

Of related interest:

STATE OF NEW YORK | CBS News (Albany) – 22 April 2015 – 'Senate passes bill to help family caregivers.' The legislation would allow patients to designate a spouse, child or other relative or friend as a caregiver and require hospitals to provide training to help them look after the patient once they leave the hospital. http://www.cbs6albany.com/news/features/top-story/stories/ny-senate-passes-bill-help-family-caregivers-24846.shtml

Ethnicity complicates patient-doctor discussion of death

THE WASHINGTON POST | Online - 22 April 2015 – Talking about death is never easy, even for medical professionals. But a new study has found that difficulty discussing end-of-life medical treatments is complicated further when there are ethnic differences that can create subtle barriers between the doctor and patient¹. A survey of more than 1,000 medical professionals by researchers at Stanford University's Medical School found that virtually all of them encountered difficulties holding end-of-life discussions with their patients ... magnified by cultural and ethnic differences that hindered discussion about end-of-life treatment, with 86% rating them as "challenging." Asian physicians reported the most struggles (91.3%), followed by African American (85.3%), Caucasian (83.5%) and Latino doctors (79.3%), according to the study. http://www.washingtonpost.com/news/local/ wp/2015/04/22/ethnicity-complicates-patientdoctor-discussion-of-death/

Primary barriers doctors report in conducting effective end-of-life conversations

- 1. Language and medical interpretation issues
- 2. Patient/family religious and spiritual beliefs about death and dying
- 3. Doctors' ignorance of patients' cultural beliefs, values and practices
- 4. Cultural differences in truth handling and decision making
- 5. Patient/family's limited health literacy
- 6. Patient/family's mistrust of doctors and the health care system

1. 'No easy talk: A mixed methods study of doctor reported barriers to conducting effective endof-life conversations with diverse patients,' *Plos One*, 22 April 2015. 2015. http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0122321

Of related interest:

- CALIFORNIA | Public News Service 23 April 2015 'Study: Doctor shortage for booming Latino population...' Over the past thirty years, the Latino population in the U.S. has risen by 243%. But during that same period, according to a recent study, the number of Latino doctors has decreased 22%.¹ <u>http://www.publicnewsservice.org/2015-04-22/health-issues/studydoctor-shortage-for-booming-latino-population-in-ca-us/a45865-1</u>
 - 'Latino physicians in the U.S., 1980-2010: A thirty-year overview from the censuses,' *Academic Medicine*, 27 January 2015. The Latino physician shortage in the U.S. has worsened over the past 30 years. The authors recommend immediate action on the national and local level to increase the supply of Latino physicians. http://journals.lww.com/academicmedicine/Abstract/publishahead/Latino Physician s in the United States, 1980 2010 .98866.aspx

Caring for Holocaust survivors at life's end

THE JEWISH WEEK | Online – 21 April 2015 – At Metropolitan Jewish Health System understands the special needs of Holocaust survivors as informed by a survey conducted with four sample populations: Holocaust survivors, second-generation Holocaust survivors, non-Holocaust survivors and non-Holocaust survivor second generation. As with my family's experience, both Holocaust survivors and the second-generation survivors do not easily access or embrace hospice care. While Holocaust survivors are not afraid of dving, they often do not speak about dving with their children because they do not want to be a burden to them. Also, second-generation Holocaust survivors do not initiate conversations about advance directives or health care wishes with their parents because they don't want to upset them, essentially creating a conspiracy of silence. One of the lessons learned was how critical it is that Holocaust survivors' voices be heard and that the clinicians and caregivers exercise a language of listening because that is how trust is built. Another was the importance of educating third parties such as social workers and other professional caregivers to facilitate these difficult conversations so care plans can be tailored to Holocaust survivor needs – assuring control over choice, and meeting them where they are religiously and spiritually. http://www.thejewishweek.com/editorial-opinion/opinion/caring-holocaustsurvivors-lifes-end

Medicare considers changing hospice care policy

U.S.A. TODAY | Online – 20 April 2015 – Medicare officials are considering changes in the hospice benefit to stop the federal government from paying twice for care given to dying patients. But patient advocates and hospice providers fear a new policy could make the often difficult decision to move into hospice care even tougher. Patients are eligible for hospice care when doctors determine they have no more than six months to live. They agree to forgo curative treatment for their terminal illness and instead receive palliative or comfort care. However, they are also still allowed Medicare coverage for health problems not related to their terminal illness, including chronic health conditions or for accidental injuries. Medicare pays a set amount to the hospice provider for all treatment and services related to the terminal illness, including doctor's visits, nursing home stays, hospitalization, medical equipment and drugs. If a patient needs treatment that hospice doesn't provide because it is not related to the terminal illness – or the patient seeks care outside of hospice – Medicare pays the non-hospice providers. The problem is that sometimes Medicare pays for care outside the hospice benefit that it already paid hospice to cover. http://www.usatoday.com/story/news/2015/04/20/kaiser-medicare-considers-changing-hospice-care-policy/25876393/

Bill would make Catholic hospitals tell sufferers about possibilities elsewhere

ILLINOIS | *The Statesmen* (New York, NY) – 17 April 2015 – A measure before Illinois lawmakers would require Roman Catholic hospitals to inform sufferers they can go elsewhere for ... particular health-related procedures and other wellness care possibilities that violate church teachings. http://www.statesmennews.com/breaking/bill-would-make-catholic-hospitals-tell-sufferers-about-possibilities-elsewhere-h2668.html

Noted in Media Watch, 2 February 2015, #395 (p.5):

- CALIFORNIA | The Times-Standard (Eureka, CA) 24 January 2015 'Church dogma a poor fit for some patients' needs.' There are 56 separate entities that manage the 629 Catholic Hospitals [in the U.S.]. 1 in 6 patients is cared for in a Catholic hospital. The U.S. Conference of Catholic Bishops has steadfastly regulated the delivery of health care throughout this extensive system.¹ <u>http://www.times-standard.com/opinion/20150124/church-dogma-a-poor-fit-for-some-patients-needs</u>
 - Ethical & Religious Directives for Catholic Health Care Services, 5th Edition, United States Conference of Catholic Bishops, 17 November 2009. <u>http://www.usccb.org/issues-andaction/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf
 </u>

N.B. In this issue of Media Watch is listed selected articles noted in past issues of the weekly report on Roman Catholic doctrine in health care.

International

Reported death rates in England

National Health Service warning over hospitals "fiddling figures" to meet targets

U.K. (England) | The Independent – 22 April 2015 – Many National Health Service (NHS) hospitals appear to be "gaming" the system to meet performance targets, in some cases changing the way they care for patients or deliberately "fiddling figures," leading healthcare experts have said. In a new report,¹ the Dr. Foster group, which pioneered transparency around hospital data in the NHS, warned that efforts to improve patient care were being "undermined" by performance measures that encouraged gaming, and were also demoralising frontline staff. Dr. Foster's report also raised new concerns that mortality statistics at some hospitals may be unreliable because of different practices in recording which patients were admitted for palliative care. Hospital standardised mortality ratios are a key measure that compares the actual number of people who die in a hospital to the number that would be expected to die. The number of expected deaths is adjusted to reflect the number of patients admitted to hospital for the purpose of specialist, end-of-life palliative care. However, Roger Taylor, a consultant at Dr. Foster, said in some cases patients who were admitted for treatment with the intention of sending them home, but were later transferred to palliative care after complications, were being recorded in the same way as patients directly admitted for palliative care. http://www.independent.co.uk/lifestyle/health-and-families/healthnews/healthcare-experts-accuse-nhs-offiddling-figures-to-meet-performancetargets-10193482.html

Extract from Dr. Foster group report

Expected death rates are adjusted to reflect the number of patients admitted for palliative care, for whom death is the expected outcome. Therefore the proportion of patients coded as receiving palliative care has an impact on a hospital's reported death rate. 1. 'Uses and Abuses of Performance Data in Healthcare,' Dr. Foster group, April 2015. <u>http://www.drfoster.com/wp-content/uploads/2015/04/Uses-and-abuses-of-performance-data-April-2015-FINAL-DIGITAL-with-cover1.pdf</u>

Updated guidance [in the U.K.] for professionals who provide care after death

U.K. (England & Wales) | National End-of-Life Care Programme & National Nurse Consultant Group – 22 April 2015 – The nurses' role at the end of life extends beyond death to provide care for the deceased person and support to their family and carers. The physical care given by nurses following death in hospitals has traditionally been referred to as "last offices." However, in this guidance the authors refer to "care after death," a term more befitting of our multi-cultural society. This guidance does not use the term "last offices" because the authors wish to move away from the link with the military and religious origins of nursing and the association with "last rites," a Christian sacrament and prayer administered to the dying, and because "last offices" only applies to the physical preparation of the body. "Care after death" is intended to reflect the differing nursing tasks involved, including on-going support of the family and carers. The physical preparation of the body itself will be called "personal care after death." The guidance is endorsed by the Royal College of General Practitioners, the Royal College of Nursing, National Health Service Improving Quality, the Royal College of Pathologists, Hospice UK, and the National Council for Palliative Care. http://www.nhsig.nhs.uk/media/2426968/care after death guidance.pdf

Ireland has "fastest rising need" for palliative care in Europe

IRELAND | The Irish Times (Dublin) - 20 April 2015 – Ireland has the fastest rising need for palliative care in Europe due to its rapidly ageing population, a new study suggests.¹ Significant increases in funding will be needed to cater for the increase in deaths from cancer, dementia and neurodegenerative diseases such as Alzheimer's, according to the study published by British and Irish researchers. Eighty per cent of the deaths recorded between 2007 and 2011 were from conditions recognised as having associated palliative care needs. This compares to 63% in the U.K. and 50% in Australia. The study shows that while deaths from cancer increased by 9.5% over this period, the increase in deaths caused by dementia and neurodegenerative diseases was far greater, as 51% and 43% respectively. In contrast, deaths from heart and respiratory disease, and stroke, are falling. It says new models of palliative care may be required to address these trends. Current funding levels are running at only half the required amount. http://www.irishtimes.com/news/health/irelan d-has-fastest-rising-need-for-palliative-carein-europe-1.2182409

Specialist Publications

'Determinants of care outcomes for patients who die in hospital in Ireland: A retrospective study' (p.12), in *BMC Palliative Care*.

'Many do not understand palliative care' (p.12), in *Irish Health*.

 'The need for palliative care in Ireland: A population-based estimate of palliative care using routine mortality data, inclusive of non-malignant conditions,' *Journal of Pain & Symptom Management*, 7 November 2014 [Noted in Media Watch, 10 November 2014, #383 (p.13)] http://www.jpsmjournal.com/article/S0885-3924(14)00548-X/abstract

Cont. next page

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.

Noted in Media Watch, 8 December 2014, #387 (p.5):

- IRELAND | The Irish Times (Dublin) 4 December 2014 'Only 1 in 3 people who want to die at home do so.' Just one out of every three people who would like to do at home actually do so, according to a new report.¹ The figures for all counties [in Ireland] are much lower than the 74% of people who told a previous survey they wanted to die at home.² The report calls for health policy to focus more on providing care in the home and community, and makes the case for the introduction key quality indicators on place of care and death as a way to monitor how well policy is being implemented. http://www.irishtimes.com/news/health/only-1-in-3-people-who-want-to-die-at-home-do-so-1.2025581
 - 'Enabling More People to Die at Home: Making the case for quality indicators as drivers for change on place of care and place of death in Ireland,' The Irish Hospice Foundation, December 2014. <u>http://hospicefoundation.ie/wp-content/uploads/2014/12/Enabling-More-People-to-Die-at-Home1.pdf</u>
 - 'Access to Specialist Palliative Care Services and Place of Death in Ireland,' The Irish Hospice Foundation, May 2013. [Noted in Media Watch, 28 October 2013, #329 (p.5)] <u>http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf</u>

End-of-life care in England

New partnership will develop palliative care services

U.K. (England) | *News Guardian* (Morpeth, Northumberland) – 20 April 2015 – Marie Curie has teamed up with Northumbria Healthcare National Health Service Foundation Trust to launch the 'Marie Cure @ Northumbria' service to develop tailored services. The partnership aims to increase the number of people being cared for in their place of choice... The first phase of the service has seen the recruitment of the first modern matron for palliative care in the Trust as well as the appointment of a team of nurses to expand the hospital liaison service... A unique feature of the service will be for the team to follow patients home in the first 24 hours of discharge to ensure a smooth transfer of care to community teams. Phase two will see the development of a new community team, incorporating a rapid response service, which will aim to reduce the number of unnecessary hospital admissions for people which can be traumatic for them and their families... http://www.newsguardian.co.uk/news/new-partnership-will-develop-palliative-care-services-1-7211184

Of related interest:

- U.K. (England) | *The Lancashire Evening Post* 25 April 2015 'Fears over cuts to "comfort blanket" hospice service.' More families have expressed their upset a special nursing service providing end-of-life care could close. St. Catherine's Hospice ... receives a smaller than average grant from the local National Health Service Clinical Commissioning Groups compared to other adult hospices. It means a funding shortfall of about £400,000, which puts its Clinical Nurse Specialist team at risk. http://www.lep.co.uk/news/health/local/fears-over-cuts-to-comfort-blanket-hospice-service-1-7228082
- U.K. (England) | BBC News 20 April 2015 'End-of-life care in Cornwall "needs improvement." A patient watchdog in Cornwall is urging healthcare providers to improve their end-of-life services. A recent study showed people were prevented from dying at home because of gaps in services.¹ <u>http://www.bbc.com/news/uk-england-cornwall-32377911</u>
 - 1. 'Place of Dying and End of Life: Final Report,' Healthwatch Cornwall, January 2015. <u>http://www.healthwatchcornwall.co.uk/wp-content/uploads/2015/01/FINAL-PLACE-OF-DYING-EOL-INSIGHTS-AND-EXPERIENCES.pdf</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLUMBIA | PanAm Post (Miami, FLA) 23 April 2015 'Colombian physicians get the final go-ahead for euthanasia.' An 18-year wait came to an end ... when Health Ministry authorities presented guidelines for Colombian doctors to perform euthanasia. The Constitutional Court ordered them to set the protocols in a February decision, after declaring the practice legal all the way back in 1997. Medical practitioners in the Andean country have routinely refused to support assisted suicide, fearing criminal charges. Even with the court judgment standing, there was simply no regulatory environment. Health Minister Alejandro Gaviría explained only adults would be able to make the decision, and a doctor must declare the patient to be in the terminal phase of his illness. If the patient is unconscious, relatives must be able to show audio, video, or written proof of his previously stated preference for assisted dying. http://panampost.com/sabrina-martin/2015/04/23/colombian-physicians-get-the-final-go-ahead-for-euthanasia/
- LUXEMBOURG | Luxemburger Wort 22 April 2015 'Luxembourg euthanasia report finds no abuses of the law.' Fifteen people were euthanised in Luxembourg during the two-year period from 2013 to 2014. A majority of procedures were carried out at hospitals, while three patients died at their retirement homes, and one person was euthanised at home. Only patients with no chance of recovery can seek authorisation for euthanasia. In most cases, the patients were being treated for terminal cancer. Three patients suffered from neurodegenerative diseases, while one person suffered a stroke. A commission charged with monitoring the implementation of the 2009 euthanasia law said no abuses had been detected and all procedures were carried out within the legal framework. The number of patients seeking euthanasia has remained stable. Previous two-year report for 2011 and 2012 saw 14 requests granted. http://www.wort.lu/en/politics/15-cases-in-2013-and-2014-luxembourg-euthanasia-report-finds-no-abuses-of-the-law-5537989d0c88b46a8ce57d97

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

Trends in engagement in advance care planning behaviors and the role of socioeconomic status

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 21 April 2015 – The authors studied three advance care planning (ACP) behaviours: 1) discussing end-of-life (EOL) care preferences: 2) providing written EOL care instructions; and, 3) appointing a durable power of attorney for health care (DPAHC). ACP increased by 12% to 23% every 2 years from 2002 to 2010. Higher household income increased the odds of having a DPAHC. Education was not associated with ACP. Socioeconomic status alone appears to play a very limited role in predicting ACP. Engagement in ACP likely depends on a constellation of many social and contextual factors. http://ajh.sagepub.com/content/early/2015/04/20/1049909115581818.abstract

Of related interest:

AMERICAN JOURNAL OF NURSING, 2015;115(5):63. 'Family- and patient-related factors impede end-of-life – care discussions.' Although survey participants believed it most acceptable for staff physicians and residents to be engaged in communication and decision making about goals of care, they considered it acceptable for advanced practice nurses, other nurses, social workers, and other allied health care professionals to initiate goals-of-care discussions and act as decision coaches. Interventions such as better communication skills training for clinicians, the use of decision aids, and greater involvement of the interprofessional health care team could improve goals of care discussions with patients and their families. http://journals.lww.com/ajnonline/Fulltext/2015/05000/Family_and_Patient_Related_Factors_Impede.27.aspx

Cont.

- BMC PALLIATIVE CARE | Online 23 April 2015 'Current advance care planning practice in the Australian community: An online survey of home care package case managers and service managers.' This survey shows low organisational advance care planning (ACP) systems and support for case managers and a lack of a normative approach to ACP across Australian Home Care Package (HCP) services. As HCPs become more prevalent it is essential that a model of ACP is developed and evaluated in this setting, so that clients have the opportunity to discuss and document their future healthcare wishes if they choose to. http://www.biomedcentral.com/content/pdf/s12904-015-0018-y.pdf
- HEART | Online 21 April 215 'Future care planning: A first step to palliative care for all patients with advanced heart disease.' Future care planning provides a framework for discussing a range of palliative care problems with patients and their families. This approach can be introduced at any time during the patient's journey of care and ideally well in advance of end-of-life care. Future care planning is applicable to a wide range of patients with advanced heart disease and could be delivered systematically by cardiology teams at the time of an unplanned hospital admission, akin to cardiac rehabilitation for myocardial infarction. http://heart.bmj.com/content/early/2015/04/21/heart.plan.2014-306724.abstract

The medicalization of bereavement: (Ab)normal grief in the DSM-5

DEATH STUDIES | Online – 23 April 2015 – This article examines the recently published changes to eliminate the bereavement exclusion (BE) from the criteria for the diagnosis of major depression in the fifth edition of the *Diagnostic & Statistical Manual*. Numerous scholars and critics have expressed concerns by calling these changes a "medicalization" of grief. This article first considers the removal of the BE and then examines the macrolevel and microlevel consequences of this medicalization of grief, including over diagnosis and overtreatment, a potential expanded market for pharmaceutical companies, and the loss of traditional and cultural methods of adapting to the loss of a loved one. http://www.tandfonline.com/doi/abs/10.1080/07481187.2014.951498#

Of related interest:

OMEGA – JOURNAL OF DEATH & DYING, 2015;71(1):3-18. 'The "how" and "when" of parental loss in adulthood: Effects on grief and adjustment.' Results [of this study] suggested that gender of the adult child and age level of the participant were important factors contributing to the grief response, and women were found to have more difficulty adjusting to the loss of a parent as well as demonstrating a more intense grief response. These results point to the importance of support from others in coping with a parent's death as well as for the counseling of bereaved persons who may be at risk for difficulties in coping with the death of a parent and enable a more precise understanding of individual grief processes across the adult lifespan. http://ome.sagepub.com/content/71/1/3.full.pdf+html

2015 White House Conference on Aging

Public health imperative of the 21st Century: Innovations in palliative care systems, services, and supports to improve health and well-being of older Americans

THE GERONTOLOGIST, 2015;55(2):245-251. A primary aim of federal aging and health policy must be promoting innovations in palliative care systems, services, and supports that improve the experience of growing old in America. Older adults must contend with increasing burden over the life course often as the result of life-limiting ... chronic illnesses as well as social and economic factors beyond their control. These are frequently shared with unpaid family caregivers who provide significant uncompensated medical care and social support to their loved ones. A public health strategy for implementing palliative care policy interventions will help to build age-friendly environments, assure availability and accessibility of palliative systems of care, essential medicines, adequate generalist-level workforce, and sustain diffusion of innovation across all levels of health and social provision. http://gerontologist.oxfordjournals.org/content/55/2/245.full.pdf+html

Cont.

Of related interest:

THE GERONTOLOGIST, 2015;55(2):302-308. 'Improving policies for caregiver respite services.' This paper provides a template for the decade ahead regarding the delivery, supply, and funding of caregiver respite services. Policy changes are needed to address these issues as concerns about our country's ability to meet future caregiving needs are growing along with our aging population. Federal initiatives and state-level policies and programs affecting respite are reviewed and directions for policy advancement are highlighted. Much more work is needed to educate caregivers and the general public about the necessity for respite beginning early in the caregiving career to prevent burnout and other adverse effects. http://gerontologist.oxfordjournals.org/content/55/2/302.full.pdf+html

N.B. These two articles appear in a special issue of *The Gerontologist* on the 2015 White House Conference on Aging. Contents page: <u>http://gerontologist.oxfordjournals.org/content/55/2.toc</u>

The parents' ability to attend to the "voice of their child" with incurable cancer during the palliative phase

HEALTH PSYCHOLOGY, 2015;34(4):446-452. The "voice of the child" becomes manifest in the parents' expressions of the child's needs and perceptions. Parents who actively searched to understand their child's inner perspective used direct and indirect strategies. Parents preferred indirect strategies when their child avoided talking or when they considered the conversation as threatening for the child, or for themselves. Even if the parents show an intense involvement in the care and support of their child; they can still have difficulty acknowledging the child's perspective. An inability to take into account the child's perspective was largely due to the parents' own struggle to cope with loss. Whether or not the voice of children approaching the end-of-life is heard, often depends on their parents' ability to give them a voice. Professional caregivers have a difficult task in supporting parents in giving their child his or her voice, while at the same time preserving their, and their parents' ability to cope. http://psycnet.apa.org/journals/hea/34/4/446/

Of related interest:

MEDICAL DECISION MAKING | Online – 21 April 2015 – 'Evolution of pediatric chronic disease treatment decisions: A qualitative, longitudinal view of parents' decision-making process.' In this study, decision making was an iterative process occurring in three distinct patterns. Understanding these and the varying elements of parents' decision processes is an essential step toward developing interventions that are appropriate to the setting and that capitalize on the skills families may develop as they gain experience with a chronic condition. http://mdm.sagepub.com/content/early/2015/04/17/0272989X15581805.abstract

Noted in Media Watch, 12 January 2015, #392 (pp.12-13):

PEDIATRICS | Online – 5 January 2015 – 'Talking with parents about end-of-life decisions for their children.' Overall, 27 physicians participated [in this study], along with 37 parents of 19 children for whom a decision to withhold or withdraw life-sustaining treatment was being considered. All physicians focused primarily on providing medical information, explaining their preferred course of action, and informing parents about the decision being reached by the team. Only in two cases were parents asked to share in the decision-making. http://pediatrics.aappublications.org/content/early/2015/01/01/peds.2014-1903.abstract

N.B. In this issue of Media Watch is listed selected articles noted in past issues of the weekly report on the decision making process in pediatric palliative care, for example:

 PROGRESS IN PALLIATIVE CARE | Online – 15 October 2012 – 'The child's voice in pediatric palliative and end-of-life care.' Although much is asked clinically and emotionally of children and adolescents who are receiving treatment for a life-threatening illness, they are not routinely asked how they experience the treatment that is intended to save or prolong their lives. Without their subjective reports (i.e., the "child's voice"), the treatment risk/benefit ratio cannot be fully known. [Noted in Media Watch, 22 October 2012, #276 (p.9)] http://www.maneyonline.com/doi/abs/10.1179/1743291X12Y.0000000035

Expansion of "right to try" legislation raises ethical, safety concerns

HEMONC TODAY | Online - 25 April 2015 - Early access to experimental drugs has historically been reserved for patients enrolled on clinical trials. In 2009, the Federal Drug Administration (FDA) revamped its 1980's expanded access program, which allows terminally ill patients ineligible for clinical trials and for whom no alternative, approved therapies exist to ask pharmaceutical companies for access to an investigational drug in their pipeline. More than 1,500 patients received an experimental treatment through the FDA's program in 2014. Now, some legislatures are going a step further by adopting so-called Right to Try legislation, intended to give terminally ill patients comparable access to investigational drugs but removing the FDA from the process. Since 2014, thirteen states have passed Right to Try laws, and legislators in 20 more states have plans to introduce similar legislation this year. "When an individual has a life-threatening illness and a terrible cancer, there is a natural sympathy," [says] Ezekiel J. Emanuel, MD, PhD, professor of medical ethics and health policy in the Perelman School of Medicine at the University of Pennsylvania... "These laws are based on the fact that a young person with a terminal cancer or illness often - and understandably - would probably try everything they can." However, concerns among those in the clinical community – who must authorize patients' requests for investigational agents - may limit the extent to which patients access treatments through such legislation. http://www.healio.com/hematology-oncology/practice-management/news/print/hemonctoday/%7Bc801b6ee-318e-4fce-9dfa-a29c597028b9%7D/expansion-of-right-to-try-legislationraises-ethical-safety-concerns

End-of-life care in Ireland

Many do not understand palliative care

IRISH HEALTH | Online – 20 April 2015 – Many people have a poor understanding of what palliative care is and who it is for, a new survey has found. Palliative care aims to provide the best quality of life to any person – adult or child – with a non-curable or serious illness, including severe heart disease, dementia and motor neurone disease. People may be provided with this type of care for a varied time frame – from a few days to a few years. However, the survey of 1,000 adults, which was carried out on behalf of the All Ireland Institute of Hospice & Palliative Care (AIIHPC), found that only 57% of people knew that palliative care is beneficial for anyone with a non-curable condition, while just 16% realised it can be provided for years. Only 45% were aware that palliative care also supports the family, friends and carers of ill people, while just 38% knew that palliative care focuses on all aspects of a person – their body, mind and spirituality. According to AIIHPC director, Paddie Blaney, these findings suggest that the public needs to be better educated about palliative care. http://www.irishhealth.com/article.html?id=24586

Of related interest:

BMC PALLIATIVE CARE | Online – 18 April 2015 – 'Determinants of care outcomes for patients who die in hospital in Ireland: A retrospective study.' More people die in hospital than in any other setting which is why it is important to study the outcomes of hospital care at end of life. This study shows significant differences in how care outcomes, including pain, were assessed by nurses, doctors and relatives. Care inputs operate in a mutually reinforcing manner to generate care outcomes which implies that improvements in one area are likely to have spill-over effects in others. Building on these findings, the Irish Hospice Foundation has developed an audit and review system to support quality improvement in all care settings where people die. http://www.biomedcentral.com/content/pdf/s12904-015-0014-2.pdf

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. <u>http://www.pcn-e.com/community/pg/file/owner/MediaWatch</u>

Old age and forgoing treatment: A nationwide mortality follow-back study in The Netherlands

JOURNAL OF MEDICAL ETHICS | Online -20 April 2015 – Forgoing treatment occurred in 37% of the total population [studied], with a significant increase in the incidence across age. The most common treatments withheld/ withdrawn were artificial hydration/nutrition, medication and antibiotics. Age-related differences were found, especially for withholding artificial hydration/nutrition among patients aged 65-79, and for withdrawing medication and antibiotics among the oldest when compared to the youngest patients. The most common reason for making the decision was 'no chance of improvement'. The likelihood of forgoing treatment due to 'loss of dignity' was higher for the oldest, as well as due to the request/wish of the patient, when compared to the youngest patients. Forgoing treatment occurred in a substantial proportion of older people, and more often than in younger age groups. The avoidance of burdensome treatment solely to prolong life suggests a better acceptance that these patients are nearing death. http://jme.bmj.com/content/early/2015/03/24/ medethics-2014-102367.abstract

In favour of medical dissensus: Why we should agree to disagree about end-of-life decisions

BIOETHICS | Online - 23 April 2014 - End-of-life decision-making is controversial. There are different views about when it is appropriate to limit life-sustaining treatment, and about what palliative options are permissible. One approach to decisions of this nature sees consensus as crucial. Decisions to limit treatment are made only if all or a majority of caregivers agree. The authors argue, however, that it is a mistake to require professional consensus in end-of-life decisions. In the first part of the article they explore practical, ethical, and legal factors that support agreement. They analyse subjective and objective accounts of moral reasoning: accord is neither necessary nor sufficient for decisions. The authors propose an alternative norm for decisions - that of "professional dissensus." In the final part of the article they address the role of agreement in endof-life policy. Such guidelines can ethically be based on dissensus rather than consensus. Disagreement is not always a bad thing. http://onlinelibrary.wiley.com/doi/10.1111/bioe.12 162/abstract

Cont next page



Of related interest:

- CRITICAL CARE MEDICINE | Online 21 April 2015 'The very elderly admitted to ICU: A quality finish?' In this study, one third of very elderly ICU patients died in hospital, many after a prolonged ICU stay while continuing to receive aggressive life-sustaining interventions. Findings raise questions about the use of critical care at the end of life for the very elderly. http://journals.lww.com/ccmjournal/Abstract/publishahead/The Very Elderly Admitted to ICU A Quality.97269.aspx
- HEALTHCARE EXECUTIVE, 2015;30(2):48-51. 'Balancing issues of medical futility.' This article focuses on the ethical and clinical issues facing physicians in relation to medical futility. Topics discussed include the concept of physiologic futility and qualitative futility and the factors that may influence the patient or his family members to demand ineffective treatments. https://www.ache.org/HEOnline/digital/heonline_index.cfm

Where do older people die? A nationwide study in France (1990–2010)

MÉDECINE PALLIATIVE | Online – 24 April 2015 – This study demonstrates that the likelihood of dying at home [in France] decreased over the last 20 years, while the proportion of older people dying in nursing homes and in hospitals significantly increased. Beyond the ethical and social concerns that these changes might raise, from a demographic and macroeconomic perspective, this process of medicalization and institutionalization of death seems unsustainable for the healthcare system. <u>http://www.sciencedirect.com/science/article/pii/S1636652215000331</u>

N.B. French language article.

Prison hospice

Hospice program provides compassionate end-of-life care in a challenging environment

ONCOLOGY NURSE ADVISOR | Online -20 April 2015 – That the U.S. prison system is filled beyond capacity is a well-known fact. What may not be so well known is that an increasingly large number of prisoners are chronically ill, elderly or aging. The number of incarcerated men and women older than 65 years has more than doubled since 2007, from 15,500 to 31,854 in 2013.¹ The number of incarcerated elderly keeps rising disproportionately. U.S. prisons increasingly resemble high-security nursing homes, as the number of aging inmates continues to soar. Many of these prisoners will be into their 70s, 80s or even older before they have finished their sentences; some are serving life without parole. Compared with the community-at-large, there is more illness among a prison population, in a place where it is difficult to be ill. Prisoners have more ... and chronic illness than the general population.² <u>http://www.oncologynurseadvisor.com/hospi</u> <u>ce-program-provides-compassionate-end-oflife-care-in-a-challenging-</u> environment/article/409943/

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-of-</u> <u>life-care-in-prisons</u>

- 'Ever more U.S. prisoners growing old behind bars,' Human Rights Watch, 9 February 2015. <u>http://www.hrw.org/news/2015/02/09/dispatches-ever-more-us-prisoners-growing-old-behind-bars</u>
- 'Essential elements of an effective prison hospice program,' American Journal of Hospice & Palliative Medicine, 2 March 2015. [Note3d in Media Watch, 9 March 2015, #400 (p.7)] http://ajh.sagepub.com/content/early/2015/02/27/1049909115574491.abstract

Hospice volunteers as facilitators of public engagement in palliative care priority setting research

PALLIATIVE MEDICINE | Online – 21 April 2015 – In England, volunteering in palliative care is well established, with the largest numbers of volunteers per 1000 inhabitants in Europe. Their role can vary considerably, from hospice-based roles (e.g., acting as "go-between" connecting patients/family and paid staff) to more public-facing responsibilities (e.g., fundraising and community work). <u>http://pmj.sagepub.com/content/early/2015/04/21/0269216315583435.extract</u>

Treatment of holistic suffering in cancer: A systematic literature review

PALLIATIVE MEDICINE | Online – 20 April 2015 – Holistic suffering is a debilitating problem for cancer patients. Although many treatments have been suggested for its alleviation, they have not been compared for effectiveness. Meaning-centred, hope-centred and stress-reduction interventions were found to be effective. Results of both psycho-educational and spiritual interventions in improving spiritual well-being were mixed. Supportive-expressive interventions – with the exception of forgiveness therapy – were not efficacious. There was little or no evidence for the efficacy of creative and healing arts and other assessed interventions such as animal therapy and hapto-therapy [the use of touch to achieve mental relaxation]. Spiritual well-being, meaning, hope and benefit finding can be positively impacted by a variety of treatment modalities. http://pmj.sagepub.com/content/early/2015/04/17/0269216315581538.abstract

Of related interest:

 RELIGIONS, 2015;6(2):476-498. 'Integrating spirituality as a key component of patient care.' Integration [of spirituality in patient care within in-patient care settings by interprofessional teams] was found to enhance person-centred care, foster connection with patients, improve HCP job satisfaction and reduce burnout among IP team members. It also facilitated awareness of the need for recognition of and a response to patient spiritual needs in a timely manner. http://www.mdpi.com/2077-1444/6/2/476/htm

Media Watch: Editorial Practice

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

Distribution

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

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4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.

5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

The transformation process for palliative care professionals: The metamorphosis, a qualitative research study

PALLIATIVE MEDICINE | Online – 20 April 2015 – During their professional activity, palliative care professionals go through a series of phases, depending on the relationship between the cost of caring and the satisfaction of caring, which can influence both the care provided to patients and families and their own personal circumstances. Being aware of this risk, and implementing self-care strategies, can protect professionals and enable them to conduct their work in an optimal manner. Reflecting on the experiences of these professionals could be useful for other health professionals. http://pmj.sagepub.com/content/early/2015/04/17/0269216315583434.abstract

Media Watch Online International INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/aboutiahpc/newsletter/2015/04/media-watch/#lived INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://www.ipcrc.net/archive-global-palliative-carenews.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-andpalliative.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-resourcecenter-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 ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://hpcconnection.ca/generalresources/in-the-news/ ONTARIO | Palliative Care Consultation Program (Oakville): http://www.acclaimhealth.ca/menu-services/palliative-careconsultation/resources/ [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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