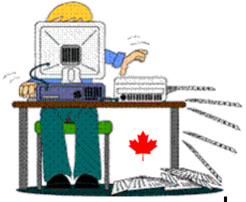
Media Watch...

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.*

22 December 2014 Edition | Issue #389



Compiled & Annotated by Barry R. Ashpole

Decision-making in end-of-life care: Scroll down to Specialist Publications and 'What should care providers do when a patient "won't budge"? (p.17), in *Journal of Clinic Ethics*.

Canada

When death is near, plain talk by doctors can lessen patients' confusion, pain

NOVA SCOTIA | *The National Post* – 19 December 2014 – The patient was gravely ill, but a lengthy note by nurses at a Halifax hospital focused on the person's next of kin. The relative, they complained, was making trouble, demanding aggressive treatment that seemed inappropriate – a source of frequent tension in Canadian health care. Stephen Workman reviewed the chart, called the relative and passed on grim but straightforward news. The patient was likely to die, and treatment such as cardio-pulmonary resuscitation would offer little help, the internal-medicine specialist at Queen Elizabeth II Health Sciences Centre recalls informing the family member. "Oh, we were never told that," the person responded, the dispute suddenly ending. "That's all right then." The surprising encounter embodied an idea some physicians say could go a long way to lessening the conflict and discomfort that marks many Canadians' deaths. As controversy builds around euthanasia, funding for palliative care and the limits of life-extending technology, these doctors advocate a bit more plain speech. Instead of tip-toeing around the question, be direct, they argue. Rather than telling someone their mother is "seriously ill," why not explain gently that the woman is dying, asks Dr. Workman, on a mission to transform the language around end of life. Being frank can make people more willing to consider palliative care in hopeless cases, or at least be more realistic about the benefits of further treatment – and motivate health professionals, the physician said. http://news.nationalpost.com/2014/12/19/when-death-is-near-plain-talk-by-doctors-can-lessen-patients-confusion-pain/

Media Watch Online

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

ALS patients too often miss out on end-of-life care

ONTARIO | *The Toronto Star* – 17 December 2014 – People with terminal illnesses such as ALS sometimes can't access end-of-life care because hospices and palliative wards typically don't have the breathing machines required by many patients, advocates say. "To have the option to be able to go into palliative care would be wonderful," said Eleanor Leggat, of ... ALS Canada. "That isn't always possible." She said some patients with the degenerative disease do die in palliative and hospice care, but that their numbers are restricted because most end-of-life facilities don't offer special "bi pap" machines that assist breathing. That means many people with the illness, a terminal ailment that deteriorates muscle activity over prolonged periods, die in acute-care wings of hospitals, where the emphasis is on treatment rather than providing a comfortable death. Rick Firth, president and CEO of Hospice Palliative Care Ontario, said ventilators and bi pap machines are considered devices that "prolong life," making them inconsistent with the tenets of end-of-life care, which focuses on pain control as the patient's life comes to a close. "The issue with a ventilator or the bi pap – that individual could live for years," said Firth. Patients in Ontario who come to die at hospices or palliative care wards are there for 18 to 21 days on average, he said. "They're not receiving any active care, and a ventilator is part of active care. They don't have any interventions that are aimed at prolonging life." Leggat ... said bi pap machines shouldn't be considered life-sustaining devices. She said the machines merely "assist breathing" – they don't breathe for the patient. "That makes them different than standard ventilators. It's a machine that's going to make things more comfortable. It certainly doesn't extend life," Leggat said. http://www.thestar.com/life/health_wellness/2014/12/17/als_patients_too_often_miss_out_on_endoflife_care_health_quality_ontario_report_says.html

> Selected articles on palliative care for patients living with amyotrophic lateral sclerosis (ALS) noted in past issues of Media Watch:
>
> - *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 September 2014 – **'Palliative care issues in ALS: An evidenced-based review.'** This article provides an evidenced-based review of palliative care options not usually addressed in national and international ALS guidelines. [Noted in Media Watch, 15 September 2014, #375 (p.7)] http://ajh.sagepub.com/content/early/2014/09/08/1049909114548719.abstract
>
> - *JOURNAL OF NEUROLOGY, NEUROSURGERY & PSYCHIATRY* | Online – 5 February 2011 – **'Palliative care in amyotrophic lateral sclerosis: Review of current international guidelines and initiatives.'** Despite an international consensus that ALS management should adopt a multidisciplinary approach, integration of palliative care into ALS management varies considerably across health care systems. [Noted in Media Watch, 14 February 2011, #188 (p.8)] http://jnnp.bmj.com/content/early/2011/02/04/jnnp.2010.232637.abstract?sid=2fb2379c-b7d2-419d-8a3b-bf6f757148c3

Doctors and nurses working with critically ill patients suffer moral distress, research finds

BRITISH COLUMBIA | Canada.com – 16 December 2014 – As more people die in intensive care units, where machines can keep diseased and failing lungs, kidneys and other organs alive and functioning in even the sickest of patients, new Canadian research is bringing into sharper focus something once rarely acknowledged: the moral distress experienced by doctors and nurses working with critically ill patients. Researchers from the University of British Columbia ... have found worrying levels of distress in the very places growing numbers of Canadians will exit this life. Half the critical care nurses surveyed, and 27% of ICU doctors, said they have considered quitting their jobs because of distress with the way patient care was handled at their hospital. The distress is being driven by end-of-life controversies ... including inconsistent care plans, families demanding doctors not withhold or stop aggressive treatments even when all hope for recovery is gone, and too much ... life support. http://o.canada.com/news/national/doctors-and-nurses-working-with-critically-ill-patients-experience-moral-distress-research-finds

Cont.

Noted in Media Watch, 8 December 2014, #387 (p.12):

- *JOURNAL OF NURSING SCHOLARSHIP* | Online – 29 November 2014 – **'Moral distress among healthcare professionals: Report of an institution-wide survey.'** Watching patient care suffer due to lack of continuity and poor communication were the highest-ranked sources of moral distress for all professional groups... Providers who left or considered leaving a position had significantly higher moral distress levels than those who never considered leaving. http://onlinelibrary.wiley.com/doi/10.1111/jnu.12115/abstract;jsessionid=7AD2D650B814F91C276CF84B1FE8E442.f04t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false

Health Quality Ontario report

Palliative care access needed for all nearing end of life...

ONTARIO | CBC News – 15 December 2014 – Dramatic improvements are needed to provide quality palliative care for all patients facing the end of their lives, including boosting the number of health providers trained in specialized care of the dying, says an Ontario health advisory agency. In a report[1] ... Health Quality Ontario said that although Canada ranks relatively high on an international index measuring "quality of death,"[2] hundreds of thousands of Canadians have no access to co-ordinated end-of-life care. Yet the issue is becoming more pressing due to the aging population: by 2026, the number of Canadians dying each year will increase by 40% to 330,000 people, with each death affecting the well-being of five other people on average – families and loved ones – or more than 1.6 million people in all, the report says. "There certainly are some real pockets of excellence," Dr. Irfan Dhalla, vice-president of Health Quality Ontario, said of the availability of comprehensive palliative care. "But there are also areas in Ontario where patients don't have access to that kind of care, and the best estimates are that only about 30% [*sic*] of people who are dying have access to specialized, team-based palliative care." http://www.cbc.ca/news/politics/palliative-care-access-needed-for-all-nearing-end-of-life-report-says-1.2873233

Access to Palliative Care in Canada

It is generally accepted that the percentage of people living with a terminal illness who have access to palliative care varies greatly across Canada. In 2007, in the only statistically significant study published to date, the Canadian Institute for Health Information estimated that people living with a terminal illness in British Columbia, Alberta, Saskatchewan and Manitoba were referred to palliative care only 35-37% of the time. This went to a low of 16% if the terminal illness was *not* cancer. In 2005, Senator Sharon Carstairs, Canada's first and only Minister with Special Responsibility for Palliative Care (2001-2003), had estimated that no more than 15% of Canadians had access to palliative care. The Quality of End-of-Life Care Coalition of Canada has been less specific – "only a small portion of those who die receive palliative care." More recently, a 2009 Université Laval press release estimated the number at 10%. The Canadian Hospice Palliative Care Association estimates have varied in recent years from a low of 15% to a high of 30%.

Access to pediatric palliative care? A 2007 study indicated that only a small percentage (5-12%) of children who die in Canada receive specialized end-of-life care. ***BRA***

1. 'Health Care for People Approaching the End of Life: An Evidentiary Framework,' Ontario Health Technology Advisory Committee. Published in *Ontario Health Technology Assessment Series*, 2014;14(14):1-45. http://www.hqontario.ca/Portals/0/Documents/eds/synthesis-report-eol-1412-en.pdf

2. 'The Quality of Death: Ranking End-of-Life Care Across the World,' Economist Intelligence Unit, July 2010. Commissioned by the Lien Foundation, Singapore. Canada was rated 5th of the forty countries that were surveyed. [Noted in Media Watch, 19 July 2010, #158 (p.3)] http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Cont.

Noted in Media Watch, 15 December 2014, #388 (pp.2,3):

- ONTARIO | Office of the Auditor General of Ontario – 9 December 2014 – **'End-of-life care in Ontario.'** Palliative care services in Ontario developed in a patchwork fashion, often being initiated by individuals who had a passion for this area of care, wherever they were located in the province. As a result, although efforts have been made to create an integrated, coordinated system to deliver palliative care, no such system exists. Chapter of auditor's report on palliative care: http://www.auditor.on.ca/en/reports_en/en14/308en14.pdf

- ONTARIO | *Ontario Health Technology Assessment Series*, 2014;14(18):1-70. **'End-of-life care interventions: An economic analysis.'** The annual cost of providing care for patients in their last year of life is estimated to account for approximately nine percent of the Ontario health care budget. As part of an effort to improve end-of-life care in the Ontario health care system, the authors evaluated the cost-effectiveness of nine quality improvement strategies. http://www.hqontario.ca/Portals/0/documents/eds/ohtas/economic-analysis-eol-care-interventions-1411-en.pdf

Selected reports on end-of-life care in Canada:

2014: 'End-of-life Care: A National Dialogue,' Canadian Medical Association, June 2014. [Noted in Media Watch, 16 June 2014, #362 (p.1)] http://www.cma.ca/multimedia/CMA/Content_Images/CMAAdvocacy/EOL_townhall_report_FINAL.pdf

2012: 'La Commission spéciale sur la question de mourir dans la dignité dépose son rapport,' Quebec Select Committee on Dying with Dignity. [Noted in Media Watch, 26 March 2012, #246 (p.2)] http://www.gouv.qc.ca/portail/quebec/pgs/commun/actualites/actualite/asurveiller_120323_soins-palliatifs/?lang=en

2011: 'Not to be Forgotten: Care of Vulnerable Canadians,' Ad-Hoc (All Party) Parliamentary Committee on Palliative & Compassionate Care. [Noted in Media Watch, 21 November 2011, #228 (p.1)] http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf

2011: 'The Royal Society of Canada Expert Panel: End-of-Life Decision Making.' [Noted in Media Watch, 21 November 2011, #228 (p.3)] http://rsc-src.ca/sites/default/files/pdf/RSCEndofLifeReport2011_EN_Formatted_FINAL.pdf

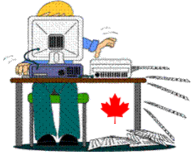
2011: 'Palliative Care: An Enforceable Canadian Human Right?' *McGill Journal of Law & Health*. [Noted in Media Watch, 26 September 2011, #220 (p.9)] http://mjlh.mcgill.ca/pdfs/vol5-1/MJLH%20Vol%20V.,%20No.%201%20-%20Shariff.pdf

2010: 'Raising the Bar: A Roadmap for the Future of Palliative Care in Canada,' Senator Sharon Carstairs, Senate of Canada. [Noted in Media Watch, 14 June 2010, #153 (p.1)] http://www.sharoncarstairs.ca/RaisingtheBarJune2010.pdf

2005: 'Still Not There: Quality End-of-Life Care,' Senator Sharon Carstairs, Ottawa. http://www.sharoncarstairs.ca/StillNotThereJune2005.pdf

2000: 'Quality End-of-Life Care: The Right of Every Canadian,' Subcommittee to update 'Of Life and Death' of the Standing Senate Committee on Social Affairs, Science & Technology. http://www.parl.gc.ca/Content/SEN/Committee/362/upda/rep/repfinjun00-e.htm

1995: 'Of Life & Death,' Report of the Special Senate Committee on Euthanasia & Assisted Suicide. http://www.parl.gc.ca/Content/SEN/Committee/351/euth/rep/lad-tc-e.htm



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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 16 December 2014 – **'"Not a controversial issue in Canada anymore": Majority support assisted suicide, poll finds.'** Canadians overwhelmingly support physician assisted suicide, and a hard core of about a third, labeled "enthusiasts," support it even in cases that do not involve pain or imminent death, but simply a wish to die. The results come from a new poll[1] ... as the Supreme Court of Canada deliberates on whether to strike down Canada's ban on assisted suicide, and Quebec tried to push through its own reform of the Criminal Code. Change is likely soon, and these strong approval numbers show that physician assisted suicide "is not a controversial issue in Canada anymore," said Arthur Schafer, director of the Centre for Professional and Applied Ethics at the University of Manitoba. "Of all the controversial issues you could name, this is the least controversial." http://news.nationalpost.com/2014/12/16/third-of-canadians-are-assisted-suicide-enthusiasts-who-support-it-in-cases-that-dont-involve-pain-or-imminent-death-poll/

  1. 'Most Canadians support assisted suicide, but under which circumstances reveal much deeper divides,' Angus Reid Institute, December 2014. Canadians express moderate to strong support for changes in legislation that would allow physicians to help patients who want to commit suicide, but the specific circumstances that might justify this course of action suggest deep divisions in public opinion. http://angusreid.org/assisted-suicide/

U.S.A.

Doctors in Massachusetts now required to offer end-of-life counseling

MASSACHUSETTS | WBUR News (Boston) – 19 December 2014 – Doctors, hospitals, nursing homes and other health providers in Massachusetts are now required to offer end-of-life counseling to terminally ill patients. It's believed to be the first such rule in the country. A similar proposal in 2009 for Medicare patients triggered claims that the government was trying to create death panels. In Massachusetts, hospitals are to identify patients who are in their last six months of life – something state regulators acknowledge is not an exact science. In Massachusetts, hospitals are to identify patients who are in their last six months of life – something state regulators acknowledge is not an exact science. A nurse or physician caring for the patient will then ask if they want to discuss care options. Do they want to be kept alive by any means possible, are they ready to stop treatment, or do they want to consider some options in between? http://commonhealth.wbur.org/2014/12/massachusetts-end-of-life-counseling

Specialist Publications

'Palliative care in 2014' (p.11), in *The ASCO Post.*

Of related interest:

- *TIME MAGAZINE* | Online – 19 December 2014 – **'An internal dialogue on how one might deal with a terminal diagnosis.'** Many people's greatest fear is of getting a terminal disease with a likely long, painful ending. The following explores how one might successfully deal with it. Imagine that you've just had a second opinion confirm that you have terminal cancer. Both doctors believe you have a few months to live, that surgery to remove the main tumor followed by aggressive chemotherapy and radiation would give you a 25% chance of living another year or two. Alternatively, you could opt to have just palliative care, which wouldn't extend your life but would address pain issues and otherwise improve your quality of life. Here is a fictional internal dialogue that such a person might have... http://time.com/3642823/living-with-dying/

The many hospices that fail patients just before they die

THE WASHINGTON POST | Online – 19 December 2014 – When a hospice patient has chosen to die at home, as they typically do, the days immediately before death are typically the most difficult, and the time when families most need a visiting nurse. But many U.S. hospices regularly fail to send a nurse out to patients in the two days preceding death, according to a *Washington Post* analysis of millions of Medicare records. About one in five U.S. hospices do not send a nurse out to patients during that critical window for at least 20% of patients, according to the data. Families that have had to handle a love one's dying days without nursing help during that trying time have referred to their hospice experience as "do-it-yourself death." Some patients die without warning, of course, and naturally almost every hospice has some patients that die without having had a recent visit. But at a typical hospice, only about 8% of patients die that way. When a hospice more regularly fails to send a nurse out during that window, experts said, the hospice probably isn't being responsive to patient needs. Indeed, the statistic – the percentage of patients at a hospice who die without a recent nursing visit – is considered by some a good indicator of hospice quality. http://www.washingtonpost.com/blogs/wonkblog/wp/2014/12/19/the-many-hospices-that-fail-patients-just-before-they-die/

Public easily swayed on attitudes toward health care law, poll finds

NATIONAL PUBLIC RADIO | Online – 18 December 2014 – Just days before the requirement [under new federal legislation] for most large employers to provide health insurance takes effect, a poll finds the public easily swayed over arguments for and against the policy. But minimal follow-up information can have a major effect on their viewpoint, the poll found. More than 40% [of survey respondents)] say (incorrectly) that the law creates a government panel to make decisions about end-of-life care for Medicare recipients. http://www.pbs.org/newshour/rundown/public-easily-swayed-attitudes-health-care-law-poll-finds/

Too little, too late for many New Yorkers seeking hospice

NEW YORK STATE | NPR News – 17 December 2014 – Despite evidence that hospices can greatly relieve discomfort, extend life and save money, and despite a generous hospice benefit available through both Medicare and Medicaid, relatively few people in New York take advantage of it, compared to elsewhere in the country. The reasons for this local gap are complicated, but Jeanne Dennis, senior vice president of hospice and palliative care at the Visiting Nurse Service of New York, says one place to start is with patients' fears. "If you're referred to hospice, it means no one expects you to get better," Dennis says. "And that is, in my mind, a threshold that's difficult for people to step over." Experts also focus on what they call medical culture, which can vary dramatically from region to region. According to this theory, physicians in the metropolitan area are specialists and sub-specialists, and institutions put a premium on treatments and tests. Even more than in other places, the goal in New York City is to cure patients rather than simply care for them. Treating and testing is just what they do – letting go isn't, says Dennis. New York has 7 out of the 10 hospitals in the country with the fewest hospice referrals. Local academic medical centers – national leaders in research – do better, but still lag behind the rest of the country in their referral rates. It's a big contrast to some hospitals around the country, particularly several in Arizona, Utah and Florida, where more than 75% of dying patients take advantage of Medicare's hospice benefit.[1] http://www.npr.org/blogs/health/2014/12/17/351145478/too-little-too-late-for-many-new-yorkers-seeking-hospice

1. 'Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness,' a report of the Dartmouth Atlas Project, Dartmouth Institute for Health Policy & Clinical Practice, Hanover, New Hampshire, April 2011. [Noted in Media Watch, 18 April 2011, #197 (p.3)] http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf

Forbidden topic in health policy debate: Cost effectiveness

THE NEW YORK TIMES | Online – 15 December 2014 – If I had a pill that would extend your life by one day, but it cost a billion dollars, it's unlikely that many people would argue that health insurance should pay for it. We all understand that while the benefit might be real and quantifiable, it's not worth the expense. But what if the pill cost a million dollars? And what if it extended your life by 10 years? Such discussions are about cost effectiveness. For the most part, we're avoiding them when we talk about health care in the U.S. Some think that discussing cost effectiveness puts us on the slippery slope to rationing, or even "death panels." After all, if we decide that the billion-dollar-for-a-day-of-life pill isn't worth it, then what's to stop us from deciding that spending a couple hundred thousand dollars to extend grandma's life for a year isn't worth it either? In fact, we in the U.S. are so averse to the idea of cost effectiveness that when the Patient Centered Outcomes Research Institute, the body specifically set up to do comparative effectiveness research, was founded, the law explicitly prohibited it from funding any cost-effectiveness research at all. As it says on its website, "We don't consider cost effectiveness to be an outcome of direct importance to patients." http://www.nytimes.com/2014/12/16/upshot/forbidden-topic-in-health-policy-debate-cost-effectiveness.html?ref=health&_r=0

Long-term health care crisis looms large

STATE OF WASHINGTON | *The Olympian* (Olympia) – 14 December 2014 – Many people don't realize that Medicaid doesn't pay for basic long-term support until the person who needs the services has spent down their savings to near nothing. Ninety percent of adults are uninsured for long-term support and services, even though 70% of those 65 and older will need those services in their lifetime. Long-term care insurance to help pay for in-home services, assisted living or nursing home care is far too expensive for many seniors. Far too often, applicants are rejected because of their existing health problems. It's a risky business with a shrinking pool of insurers. Several factors add to the crisis. The percent of Washingtonians 65 and older is expected to nearly double by 2030. And too many baby boomers are not financially prepared to pay for long-term care – 25% of people 65 and older have less than $25,000 in savings. Unpaid family caregivers provide 87% of all long-term service and support in Washington, and that care is valued at some $11.6 billion annually. But the supply of unpaid family caregivers is expected to decline by 43% over the next 15 years. http://www.theolympian.com/2014/12/14/3474270/long-term-health-care-crisis-looms.html?sp=/99/109/

Of related interest:

- *THE NEW YORK TIMES* | Online – 15 December 2014 – **'Moving away from nursing homes.'** What happens now to America's seniors when family members cannot care for them and assisted living is not affordable or no longer suitable for those with advanced physical or mental disabilities? For those who lack financial resources to pay for round-the-clock professional care at home, is the sterile hospital-like environment of a nursing home the only option... http://well.blogs.nytimes.com/2014/12/15/moving-away-from-nursing-homes/?ref=health&_r=0

Withholding life-sustaining treatment

Appeals court rules on state doctors' obligations

WISCONSIN | Associated Press – 11 December 2014 – The government has no constitutional obligation to provide health care to patients in state doctors' care, a state appeals court ruled. The 4th District Court of Appeals agreed with a ruling by Dane County Circuit Court Judge Daniel Moeser, who said the government doesn't have a constitutional obligation "to provide health care, offer services or act to save a person's life." The appeals court judges cautioned that the ruling wasn't an opinion on doctors' potential obligations or whether the actions violate tort law or professional codes... http://www.bellinghamherald.com/2014/12/11/4023264_appeals-court-rules-on-state-doctors.html?sp=/99/321/&rh=1

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NBC NEWS | Online – 16 December 2014 – **'Most U.S. doctors now support aid in dying: Survey.'** For the first time, most U.S. doctors – 54% – favor aid in dying, backing the rights of patients with an incurable illness to seek "a dignified death," according to a survey of more than 21,000 doctors...[1] The survey language ... read: "I believe terminal illnesses such as metastatic cancers or degenerative neurological diseases rob a human of his/her dignity. Provided there is no shred of doubt that the disease is incurable and terminal, I would support a patient's decision to end their life, and I would also wish the same option was available in my case should the need arise. Physicians are healers. We are not instruments of death. This is wrong." http://www.nbcnews.com/health/health-news/most-u-s-doctors-now-support-aid-dying-survey-n269691

    1. Medscape Ethics Report 2014, Part 1: Life, Death, and Pain – survey findings: http://www.medscape.com/features/slideshow/public/ethics2014-part1#2

- NEW JERSEY | NJ.com – 15 December 2014 – **'After emotional hearing, reluctant N.J. Senate panel releases Aid in Dying bill.'** The Senate Health, Human Services & Senior Citizens Committee voted 4-3 to let the Aid in Dying bill proceed to the full 40-member Senate, but did so in a way that registered committee members concern and uncertainty by approving it "without recommendation." Patients suffering from a terminal disease who want to end their lives would have to first verbally request a prescription from their attending physician, followed by a second request at least 15 days later and one request in writing signed by two witnesses, according to the bill passed the Assembly last month. The patient's physician would have to offer the patient a chance to rescind their request. A consulting physician would then be called upon to certify the original diagnosis and reaffirm the patient is capable of making a decision. http://www.nj.com/politics/index.ssf/2014/12/with_reluctance_nj_senate_panel_releases_aid_in_dying_bill.html

International

End-of-life care in Scotland

Caring for people in the last days and hours of life

U.K. (Scotland) | The Scottish Government – 19 December 2014 – This National Statement confirms the 'Caring for people in the last days and hours of life' guidance and four principles as the framework for further planning and development at a local level across Scotland.[1] In December 2013 the Scottish Government accepted the recommendation that The Liverpool Care Pathway should be phased out in Scotland by December 2014. This statement confirms the current position. http://www.scotland.gov.uk/Publications/2014/12/9301

1. The guidelines complement 'Caring for people in the last days and hours of life,' National Health Service Scotland, December 2013. [Noted in Media Watch, 23 December 2013, #337 (p.8)] http://www.scotland.gov.uk/Resource/0044/00441053.pdf

Noted in Media Watch, 19 May 2014, #358 (p.3):

- U.K. (Scotland) | Scottish Partnership for Palliative Care – 16 May 2014 – **'Call for a new Scottish Government strategy to improve end-of-life care in Scotland.'** Marie Curie Cancer Care and the Scottish Partnership for Palliative Care calls on the Scottish Government to act on recent promises to replace *Living & Dying Well: A national action plan for palliative and end-of-life care in Scotland*. http://www.palliativecarescotland.org.uk/content/publications/Are-We-Living-and-Dying-Well-Yet-FINAL-REPORT.pdf

End-of-life care in Korea

Most terminal patients choose treatment over hospice care

KOREA | *The Korea Herald* (Seoul) – 18 December 2014 – Nearly all patients suffering from late-stage cancer actively fight the disease rather than choose hospice care, a report by a state-run institute showed. Some 97.4% of medical procedures on late-stage cancer patients are active treatment such as chemotherapy, surgery and undergoing a battery of tests, while only 2.6% are focused on hospice or palliative care aimed at managing the patients' pain, according to researchers at government-affiliated Health Insurance Policy Research Institute. The report was another indicator that preparing for death under hospice care is still a relatively new concept in Korea. In a recent survey by Ulsan University Hospital, fewer than 70% of the respondents were familiar with the concept. http://www.koreaherald.com/view.php?ud=20141218000926

Noted in Media Watch, 9 December 2013, #335 (p.5):

- KOREA | *The JoongAng Daily* (Seoul) – 29 November 2013 – **'Guidelines detail end-of-life terms.'** Following years of public discussion on how to ensure terminally ill patients live their last moments with dignity, the Ministry of Health & Welfare unveiled the first draft of its "death with dignity" guidelines. The government is seeking to allow terminally ill patients to forgo life-sustaining medical care in the event that they sign an "advanced directive," which indicates that treatment will be withdrawn when there is no chance of recovery. http://koreajoongangdaily.joins.com/news/article/article.aspx?aid=2981235

Noted in Media Watch, 14 October 2013, #327 (p.9):

- *CRITICAL CARE* | Online – 4 October 2013 – **'Survey of controversial issues of end-of-life treatment decisions in Korea: Similarities and discrepancies between healthcare professionals and the general public.'** Over 50% [of survey respondents] thought that end of life treatment decisions should be made through discussions between the physician and the patient's family. For conflict resolution, 75% of Koreans not working in healthcare preferred direct settlement between the medical staff and the patient's family, while 55% of healthcare professionals preferred the hospital ethics committee. http://ccforum.com/content/pdf/cc13042.pdf

Global life expectancy rises by about six years, study finds

CTV NEWS (Canada) | Online – 17 December 2014 – People around the world lived on average to a ripe old age of 71.5 in 2013, up from 65.3 in 1990, a study said, noting the gains came despite big increases in liver cancer and chronic kidney deaths.[1] Global life expectancy rose by 5.8 years in men and 6.6 years in women between 1990 and 2013. The increase was attributed to falling death rates from cancers (down by 15%) and cardiovascular disease (down by 22%) in high-income regions of the world. In less affluent regions, it was attributed to rapidly declining death rates for diarrhoea, lower respiratory tract infections, and neonatal disorders. http://www.ctvnews.ca/health/global-life-expectancy-rises-by-about-six-years-study-finds-1.2153371

1. 'Global, regional, and national age-sex specific all-cause and cause-specific mortality for 240 causes of death, 1990-2013: A systematic analysis for the Global Burden of Disease Study 2013,' *The Lancet*, 17 December 2014. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)61682-2/abstract

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

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

Ambulance Data Project for End-of-Life Care

U.K. (England) | National End-of-Life Care Intelligence Network – 15 December 2014 – The North West and the South East coast ambulance services participated in a joint project with the Network to explore collection and use of ambulance data in supporting delivery of end-of-life care. The project examined the information available to ambulance services about people approaching the end of life and the role of ambulance services at this time, including emergency calls and rapid transfers home to die. The report includes recommendations for supporting ambulance professionals in their role which include better identification of the dying patient and unified national ambulance data. http://www.endoflifecare-intelligence.org.uk/resources/publications/ambulance

Noted in Media Watch, 27 January 2014, #342 (p.11):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2014;20(1):37-44. **'Challenges U.K. paramedics currently face in providing fully effective end-of-life care.'** Paramedics play an integral part in community end-of-life care (EoLC) in the U.K., especially given the lack of out-of-hours cover by palliative care specialists. This article highlights some of the barriers to effective paramedic EoLC provision and introduces examples of collaborative work in the U.K. that aim to overcome these. Given the similarities in the international evolution of paramedic education, readers from other countries will be able to relate to these findings. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=102856;article=IJPN_20_1_37_44

Elder care in England

Elderly at risk at hundreds of care homes

U.K. (England) | *The Telegraph* – 13 December 2014 – More than 500 care homes and services for the elderly put frail residents at risk in the past year because their staff were not up to the job. New figures [from the Care Quality Commission] show that of the 5,332 care homes and home-help services assessed in the last 12 months, 522 failed to meet the most basic legal standards for staffing. The findings suggest tens of thousands of elderly and disabled adults across England are being looked after by workers who are not properly trained, have no relevant experience, or in some cases may even have criminal records. Some 366,000 elderly and disabled adults are living in care homes and nursing homes in England. A further 444,000 are estimated to be receiving care services in their own homes... Under the Health & Social Care Act 2008, all care homes and nursing agencies providing home help must ensure their workers are of good character, have the skills, experience and qualifications necessary to do their jobs, and are physically and mentally fit for work. http://www.telegraph.co.uk/health/elderhealth/11292393/Elderly-at-risk-at-hundreds-of-care-homes.html

Of related interest:

- U.K. | BBC News – 14 December 2014 – **'The hidden lives of those who care.'** While nobody sets out to be an unpaid carer, it is a job more than six million people currently perform, according to the 2011 Census. This hidden workforce, thought to save the economy £119 billion a year, is drawn from all ages and backgrounds. http://www.bbc.com/news/uk-england-30290967

- IRELAND | *The Irish Mirror* (Dublin) – 14 December 2014 – **'More than one fifth of Ireland's over-85s are in care homes, new figures show.'** Ireland has the third highest number of elderly people living in care institutions in the European Union – and is sleepwalking into an ageing population crisis. According to the numbers [from the European Consensus Hub], over a fifth of Irish people over 85, 22.6%, are not living in private households. The data largely refers to those living in "collective institutions" but can also take into account the homeless. http://www.irishmirror.ie/news/irish-news/health-news/more-one-fifth-irelands-over-85s-4804533

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GERMANY | *The Local* – 19 December 2014 – The German Ethics Council said the law should not be changed to permit assisted suicide... Council members agreed with the Federal Medical Council (Bundesärztekammer) that doctors should not routinely be asked to help patients commit suicide. But they argued that in "exceptional circumstances," decisions of conscience by a doctor in the context of a "trusting doctor-patient relationship" should be respected. The decision is a blow to a cross-party initiative to legalize the practice put forward by Bundestag vice-president Peter Hintze of the Christian Democratic Union and Social Democratic Party deputy leader Carola Reimann. http://www.thelocal.de/20141219/ethics-council-rejects-assisted-suicide-terminal-illness-dying-law-bill

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

American Society of Clinical Oncology

Palliative care in 2014

THE ASCO POST | Online – 15 December 2014 – Each person battling a serious illness has unique priorities, and it is our job to mobilize the health-care system in the service of each patient and family. The patient is not just another cog in the system, and we must remember that the sole reason for palliative care is to rekindle the roots of the healing profession. It's about the patient as a person. The cost element, which is important in overall health care, is not what palliative care is all about. However, there are analyses demonstrating that palliative care intervention prevents many unnecessary emergency room visits, which of course saves the system money. There are other examples where palliative care saves money by addressing symptoms before they become emergencies. The cost-saving issues are a side effect of delivering better quality of care, but they are not part of the intended role of palliative care. That's an important distinction because, in palliative care, we often advocate for very expensive therapies if we think they are beneficial for our patients. http://www.ascopost.com/issues/december-15,-2014/palliative-care-in-2014.aspx

The compensatory nature of personhood

ASIAN BIOETHICS REVIEW, 2014;6(4):332-342. At the crux of modern end-of-life care is a patient-centred approach focused upon maintaining the personhood of each individual patient. All too often, determinations of personhood are led by clinical considerations – such as their conscious and functional levels and/or by their relational ties – and have served to inform critical ethical debates in end-of life care, such as terminal sedation and euthanasia... Recent clinical studies ... suggest that these prevailing concepts that underpin the definitions of the poorly delineated terms, "person" and "personhood," are inadequate and serve to highlight "the complexities and contradictions underlying their apparent simplicity" ... While some look to neuroscience for an objective basis of a criterion for "personhood," others rely on philosophical and theological sources for clarity... As a result, there are contrasting views on the concept of personhood... Efforts to appropriately contextualise the concept of personhood within the end-of-life setting appear to have come a head with suggestions that unconscious terminally ill patients ought to be considered devoid of personhood, "socially dead," and thus ought to be considered to be in a state indifferentiable from biological death as a result of their potentially irreversible loss of consciousness till their biological demise... The impact of such a suggestion has significant repercussions on the practice of palliative care at the end of life where sedation and unconsciousness are not uncommon either by virtue of ongoing disease processes or as a result of treatment of their symptoms... http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/asian_bioethics_review/v006/6.4.alsuwaigh.html

Cont.

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 16 December 2014 – **'Eliciting personhood within clinical practice: Effects on patients, families and health care providers.'** The authors developed the Patient Dignity Question (PDQ) as a simple means of inquiring about personhood: "What do I need to know about you as a person to give you the best care possible?" 126 participants (66 patients; 60 family members) responded to the PDQ; 99% indicated the summaries were accurate; 97% permitted the summary to be placed in the chart; 93% felt the information was important for health care providers to know; and 99% would recommend the PDQ for others. 137 health care providers completed 293 evaluations of individual PDQs; 90 % indicated that they learned something new from it; 64% that they were emotionally affected by it; 59% that it influenced their sense of empathy; and 44% that it influenced their care. http://www.jpsmjournal.com/article/S0885-3924(14)00914-2/abstract

A fine balance: Reconsidering patient autonomy in light of the United Nations Convention on the Rights of Persons with Disabilities

BIOETHICS | Online – 10 December 2014 – The Convention ... is increasingly seen as driving a paradigm shift in mental health law, particularly in relation to the understanding that it requires ... a shift from substituted to supported decisions. This article identifies two competing moral commitments implied by this shift, both of which appeal to the notion of autonomy. Because of these, the Convention is in tension with more general calls in the medical ethics literature for preserving patient autonomy through support. The competing commitments within the Convention also present a particular challenge in putting the support it requires into practice. A discursive control account of freedom is used to develop some practical guidelines for navigating this new moral territory.http://onlinelibrary.wiley.com/doi/10.1111/bioe.12133/abstract

One size fits all? On patient autonomy, medical decision-making, and the impact of culture

MEDICAL LAW REVIEW | Online – 16 December 2014 – While both medical law and medical ethics have developed in a way that has sought to prioritise patient autonomy, it is less clear whether it has done so in a way that enhances the self-determination of patients from non-western backgrounds. The authors consider the desire of some patients from non-western backgrounds for family involvement in decision-making and argue that this desire is not catered for effectively in either medical law or medical ethics. They examine an alternative approach based on relational autonomy that might serve both to allow such patients to exercise their self-determination while still allowing them to include family members in the decision-making process. http://medlaw.oxfordjournals.org/content/early/2014/12/16/medlaw.fwu032.abstract

Care provided and care setting transitions in the last three months of life of cancer patients: A nationwide monitoring study in four European countries

BMC CANCER | Online – 16 December 2014 – Of 2,037 identified patients from four countries [Belgium (BE), The Netherlands (NL), Italy (IT) and Spain (ES)], four out of five lived at home or with family in their last year of life.[1] Over 50% of patients had at least one transition in care settings in the last three months of life; one third of patients in BE, IT and ES had a last week hospital admission and died there. In the last week of life, a treatment goal was adopted for 80-95% of those having palliation/comfort as their treatment goal. Cross-country differences in end-of-life care provision included GPs in NL being more involved in palliative care (67%) than in other countries (35-49%) ... and end-of-life topics less often discussed in IT or ES. Preference for place of death was less often expressed in IT and ES (32-34%) than in BE and NL (49-74%). Although palliative care was the main treatment goal for most cancer patients at the end of life in all four countries, frequent late hospital admissions and the symptom burden experienced in the last week of life indicates that further integration of palliative care into oncology care is required in many countries. http://www.biomedcentral.com/content/pdf/1471-2407-14-960.pdf

Cont.

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 18 December 2014 – **'Implementation of a hospital-based home palliative care at regional level: A quantitative study of the *Ospedalizzazione Domiciliare Cure Palliative Oncologicheprogram* in Lombardy.'** Targets of 65% deaths at home were achieved across the region, with temporary re-hospitalization below 4.4%. The average pathway length stood above one month; intensity of care stood above ministerial and regional standards, with most home visits performed by nurses and physicians. The implementation of the regional program revealed three strengths (prompt identification and enrollment of eligible patients, and quantity of home visits) and two weaknesses (limited enrollment from general practitioners and multi-disciplinarity). This highlights opportunities for policy-makers to invest on regional protocols of hospital-based home palliative care to reduce trends of institutionalized dying and align providers to homogeneous results. http://pmj.sagepub.com/content/early/2014/12/18/0269216314558156.abstract

- *PALLIATIVE MEDICINE* | Online – 18 December 2014 – **'Preparing palliative home care nurses to act as facilitators for physicians' learning: Evaluation of a training programme.'** Training palliative home care team nurses as facilitator of general practitioners' workplace learning is a feasible, but complex intervention. Training expert palliative care nurses to facilitate general practitioners' workplace learning requires careful and individualised mentoring. http://pmj.sagepub.com/content/early/2014/12/18/0269216314560391.abstract

- *PALLIATIVE MEDICINE* | Online – 17 December 2014 – **'Doctors' and nurses' views and experience of transferring patients from critical care home to die: A qualitative exploratory study.'** The practice of transferring critically ill patients home to die is a rare event in the U.K., despite the positive view of health care professionals. Challenges to service provision include patient care needs, uncertain time to death, and the view that transfer to community services is a complex, highly time-dependent undertaking. While there is evidence of this choice being honoured and delivered for some of the critical care population, it remains debatable whether this will become a conventional practice in end of life in this setting. http://pmj.sagepub.com/content/early/2014/12/16/0269216314560208.abstract

Predictors of spiritual care provision for patients with dementia at the end of life as perceived by physicians: A prospective study

BMC PALLIATIVE CARE | Online – 19 December 2014 – Palliative care indicators were not predictive of spiritual end-of-life care; palliative care in dementia may need better defining and implementation in practice. Physician-family communication upon admission may be important to optimize spiritual caregiving at the end of life. According to the physicians [i.e., study participants], spiritual end-of-life care was provided shortly before death to 20.8% (43/207) of the residents. Independent predictors of spiritual end-of-life care were: families' satisfaction with physicians' communication at baseline ... and faith or spirituality very important to resident whether ... of importance to the physician. Further, female family caregiving was an independent predictor... http://www.biomedcentral.com/content/pdf/1472-684X-13-61.pdf

Of related interest:

- *JOURNAL OF RELIGION & HEALTH* | Online – 18 December 2014 – **'Embracing a broad spirituality in end-of-life discussions and advance care planning.'** A broad view of spirituality is needed, one that may involve traditional religious beliefs, but also includes personal understandings of what is holy or sacred. Embracing this broad practice of spirituality will help both familial and professional caregivers honor an essential aspect of end-of-life discussions and promote greater discernment of the deep meaning in advance care documents. http://link.springer.com/article/10.1007/s10943-014-9988-y

The association between exaggerations in health related science news and academic press releases: Retrospective observational study

BRITISH MEDICAL JOURNAL | Online – 10 December 2014 – Forty-percent of the press releases [analyzed by the authors] contained exaggerated advice, 33% contained exaggerated causal claims, and 36% contained exaggerated inference to humans from animal research. There was little evidence that exaggeration in press releases increased the uptake of news. Improving the accuracy of academic press releases could represent a key opportunity for reducing misleading health related news. http://www.bmj.com/content/349/bmj.g7015

From the archives:

- *AMERICAN MEDICAL WRITERS ASSOCIATION JOURNAL*, 1999;14(1);32-42. **'A journalist's guide to writing health stories.'** Most journalists have little formal training in assessing the validity of evidence that bears on health issues, so inaccurate or deceptive reporting seems common. https://www.k4health.org/sites/default/files/136485702-a-journalists-guide-to-writing-health-stories_0.pdf

Palliative care in Africa

eCANCER | Online – Accessed 15 December 2014 – Cultural traditions and modern healthcare align in this special issue of *eCancer* focusing on palliative care in Africa. Five original articles from on-the-ground experts, and an editorial by Professor Anne Merriman, highlight the multiple angles of this complex topic. Journal contents page: http://ecancer.org/special-issues/6-palliative-care-in-africa.php

Noted in Media Watch, 20 May 2013, #306 (p.6):

- AFRICA | *Think Africa Press* – 15 May 2013 – **'Easing Africa's pain: The need for palliative care.'** Millions of patients in Africa with advanced cancer, HIV or other illnesses live and die in extreme pain every year. And their numbers grow year by year. In 2007, there were over 700,000 new cancer cases and nearly 600,000 cancer-related deaths in Africa, though those figures do not include the many people who are misdiagnosed or never diagnosed at all. http://thinkafricapress.com/health/easing-africas-pain-need-palliative-care

The integration of early palliative care with oncology care: The time has come for a new tradition

JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK, 2014;12(12):1763-1771. The past decade has brought forth innovative research that questions the traditional oncology care model for patients with advanced cancer. Through integrating palliative care (PC) early into the disease course for patients with a poor-prognosis cancer, three seminal studies showed improvements in outcomes, ranging from quality of life, mood, patient satisfaction, prognostic understanding, health service use, and possibly survival.[1-3] The results of these paradigm-changing studies generate questions about the mechanisms through which early PC improves patient outcomes and about how best to disseminate early PC models. This article reviews the three studies, examines challenges to conducting PC research, and considers future directions in the field. http://www.jnccn.org/content/12/12/1763.full

1. 'Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The Project ENABLE II Randomized Controlled Trial,' *Journal of the American Medical Association*, 19 August 2019. Compared with participants receiving usual oncology care, those receiving a nurse-led, palliative care-focused intervention addressing physical, psychosocial, and care coordination provided concurrently with oncology care had higher scores for quality of life and mood, but did not have improvements in symptom intensity scores or reduced days in the hospital or ICU or emergency department visits. [Noted in Media Watch, 24 August 2009, #111 (p.6)] http://jama.jamanetwork.com/article.aspx?articleid=184422

Cont.

2. 'Early palliative care for patients with metastatic non–small-cell lung cancer,' *New England Journal of Medicine*, 18 August 2010. Although the authors' findings must be replicated in a variety of care settings and cancer populations, the results nonetheless offer great promise for alleviating distress in patients with metastatic disease and addressing critical concerns regarding the use of health care services at the end of life. [Noted in Media Watch, 23 August 2010, #163 (p.8)] http://www.nejm.org/doi/full/10.1056/NEJMoa1000678#t=articleTop

3. 'Early palliative care for patients with advanced cancer: A cluster-randomised controlled trial,' *The Lancet*, 19 February 2014. Although the difference in quality of life was non-significant at the primary endpoint, this trial shows promising findings that support early palliative care for patients with advanced cancer. [Noted in Media Watch, 24 February 2014, #346 (p.1)] http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)62416-2/abstract

Noted in Media Watch, 8 December 2014, #387 (p.14):

- *THE ONCOLOGIST* | Online – 5 December 2014 – **'Integration of oncology and palliative care: A systematic review.'** Both the American Society of Clinical Oncology and the European Society for Medical Oncology strongly endorse integrating oncology and palliative care; however, a global consensus on what constitutes integration is currently lacking. http://theoncologist.alphamedpress.org/content/early/2014/12/04/theoncologist.2014-0312.abstract

Of related interest:

- *BMC PALLIATIVE CARE* | Online – 16 December 2014 – **'Attitudes and referral patterns of lung cancer specialists in Europe to Specialized Palliative Care and the practice of Early Palliative Care.'** Despite good availability of specialized palliative care (PC) services at institutions of members of the European Organisation for Research & Treatment Lung Cancer Group, and most respondents expressing positive attitudes towards (PC), their practice involved referral of patients to PC late in the disease trajectory, hence lung cancer specialists in Europe have not adopted the practice of early (PC) concurrent with active oncological care. http://www.biomedcentral.com/content/pdf/1472-684X-13-59.pdf

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy 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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1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Conducting research interviews with bereaved family carers: When do we ask?

JOURNAL OF PALLIATIVE MEDICINE | Online – 17 December 2014 – Interviews with bereaved family carers to examine the end-of-life experience of the deceased are important tools for palliative care researchers, but the ethics of approaching the bereaved when they are grieving and vulnerable is often debated. The aim of this study was to explore the insights of bereaved family carers about the most appropriate time to be involved in a research interview about the end of life and death of their family member. Most family carers (86%) [interviewed] feel comfortable being interviewed about the death of their family member within the first 5 months of bereavement, with 43% reporting they could be interviewed within weeks after death. Family carers reported that recall would be better earlier in bereavement and felt it may be helpful to them to talk about their experiences earlier. They said bereaved people should be allowed to decide for themselves when to be involved in an interview. These findings indicate that interviews with the bereaved may be most fruitful for researchers and beneficial to family carers when they are allowed to make the choice about timing for themselves, beginning weeks after the death of their family member. http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0320

Of related interest:

- *BEREAVEMENT CARE*, 2014;33(3):111-112. **'Handling bereavement in the workplace – a guide for employers.'** Grief cannot be left at the door by staff when they come to work, and how they are treated by their employers at this vulnerable time will have important consequences for both. The authors discuss the recently published Advisory, Conciliation & Arbitration Service guidance for employers on handling bereavement in the workplace.[1] http://www.tandfonline.com/doi/full/10.1080/02682621.2014.980986

  1. 'Managing bereavement in the workplace: A good practice guide,' Advisory, Conciliation & Arbitration Service, September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.15)] http://www.acas.org.uk/media/pdf/0/m/Managing-bereavement-in-the-workplace-a-good-practice-guide.pdf

Values important to terminally ill African American older adults in receiving hospice care

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE, 2014;10(4):338-355. While racial disparity in the use of hospice care by older African Americans is widely acknowledged, little is known about the values that they consider as important in receiving health care services along with direct experiences with having these values respected by hospice care providers. Using individual, face-to-face interviews, data were collected from African American hospice patients about their experiences in hospice care. Resulting themes included: dying at home, open communications, independent decision-making, autonomy in daily life, unwillingness to be a burden, and relationships. http://www.tandfonline.com/doi/abs/10.1080/15524256.2014.975317

Noted in Media Watch, 20 January 2014, #341 (p.10):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 9 January 2014 – **'Terminally ill African American elders' access to and use of hospice care.'** The underuse of hospice care by terminally ill African American elders suggests that they are suffering when hospice care could offer quality end-of-life care. The authors provide insights into strategies used to overcome access barriers posed by income, health insurance and administrative procedure, as well as the role religion, family, information and health beliefs played in using hospice. http://ajh.sagepub.com/content/early/2014/01/09/1049909113518092.abstract

Noted in Media Watch, 7 October 2013, #326 (pp.6-7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 October 2013 – **'Barriers to end-of-life care for African Americans from the providers' perspective: Opportunity for intervention development.'** African Americans are less likely to complete advance directives and enroll in hospice. Barriers included: lack of knowledge about prognosis, desires for aggressive treatment, family members resistance to accepting hospice, and lack of insurance. http://ajh.sagepub.com/content/early/2013/10/03/1049909113507127.abstract

Barriers associated with the implementation of an advance care planning program in a prison setting

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE, 2014;10(4):322-337. Advance care planning is considered a best practice within health care. However, the extent to which planning occurs within prison settings is unknown. Through the course of implementing an advance care planning program for aging and dying offenders at a medical classification center, multiple barriers were identified that need to be addressed systemically to ensure the medical wishes of offenders were known and honored. This article outlines the barriers and the steps that were taken to create systems change to promote and sustain advance care planning. http://www.tandfonline.com/doi/abs/10.1080/15524256.2014.975320

> **N.B.** The quality of end-of-life care in the corrections or prison system has been highlighted in Media Watch on a regular basis. An updated compilation of articles, reports, etc., noted in the weekly report was recently posted on the Palliative Care Community Network website: http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons

MEDSCAPE Ethics Report 2014, Part 1: Life, Death, and Pain

MEDSCAPE | Online – 16 December 2014 – Physicians grapple with many wrenching decisions throughout their medical careers. Some situations involve whether to prolong or bring an end to patients' lives; others spark heated debates among physicians with different values. More than 21,000 physicians told *Medscape* how they feel about medicine's most critical issues. Respondents included more than 17,000 U.S. and 4,000 European physicians. This slideshow reports the U.S. physicians' results. Representative respondent comments are also shown, to shed more light on the issues at hand. http://www.medscape.com/features/slideshow/public/ethics2014-part1#1

Difficult conversations: From diagnosis to death

THE OCHSNER JOURNAL, 2014;14(4): 712-717. Although many published guidelines address difficult communication, communication training is lacking. Consequently, many clinicians may have difficulties with, or in the worst-case scenario, avoid delivering bad news and discussing end-of-life treatment. Clinicians also struggle with how to have the last conversation with a patient and how to support patient autonomy when they disagree with a patient's choices. There is a clinical imperative to educate physicians and other healthcare workers on how to effectively deliver information about a patient's health status, diagnostic avenues to be explored, and decisions to be made at critical health junctions. Knowing how to implement the most rudimentary techniques of motivational interviewing, solution-focused brief therapy, and cognitive behavioral therapy can help physicians facilitate conversations of the most difficult type to generate positive change in patients and families and to help them make decisions that minimize... http://www.ochsnerjournal.org/doi/abs/10.1043/1524-5012-14.4.712

What should care providers do when a patient "won't budge"?

JOURNAL OF CLINICAL ETHICS, 2014;25(3): 179-188. Patients who face making a high-stakes decision – whether or not to accept a lifesaving intervention – may make a decision that their care providers believe is deeply and dangerously mistaken. How can care providers best help patients in such situations? If a determination of competency exam seems to be in the patients' best interests, how can care providers refer their patients without betraying their patients' trust, given that the trust between patients and care providers is one of the most powerful tools care providers have in working with patients? Ethically, is it possible for care providers to participate in determinations of competency for their own patients? The author presents approaches that care providers can adopt to help patients who "won't budge" when making what appear to be dangerously erroneous choices regarding lifesaving interventions. http://www.clinicalethics.com/

Non-medical prescribing in palliative care: A regional survey

PALLIATIVE MEDICINE | Online – 12 December 2014 – The U.K. is considered to be the world leader in nurse prescribing, no other country having the same extended non-medical prescribing rights. Arguably, this growth has outpaced research to evaluate the benefits, particularly in areas of clinical practice where patients have complex co-morbid conditions such as palliative care. This is the first study of non-medical prescribing in palliative care in almost a decade. While this survey found non-medical prescribers have embraced the 2012 legislative changes and prescribe a wide range of drugs for cancer pain, the authors also identified scope to improve the transition from qualified to active non-medical prescriber by reducing the time interval between the two. http://pmj.sagepub.com/content/early/2014/12/10/0269216314557346.abstract

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2014/12/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

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BMC MEDICAL ETHICS* | Online – 20 December 2014 – **'Trust increases euthanasia acceptance: A multilevel analysis using the European values study.'** This study tests how various kinds of trust impact attitudes toward euthanasia among the general public. The indication that trust might have an impact on euthanasia attitudes is based on the slippery slope argument, which asserts that allowing euthanasia might lead to abuses and involuntary deaths. Adopting this argument usually leads to less positive attitudes towards euthanasia. Tying in with this, it is assumed here that greater trust diminishes such slippery slope fears, and thereby increases euthanasia acceptance. Trust seems to be a noteworthy construct to explain differences in attitudes towards euthanasia, especially when drawing cross-country comparisons. Therefore, it should be added to the existing literature on correlates of euthanasia attitudes. http://www.biomedcentral.com/content/pdf/1472-6939-15-86.pdf

- *JOURNAL OF MEDICAL ETHICS*, 2015;41(1):40-43. **'The debate about physician assistance in dying: 40 years of unrivalled progress in medical ethics?'** Some issues in medical ethics have been present throughout the history of medicine, and thus provide us with an opportunity to ascertain: 1) whether there is progress in medical ethics; and, 2) what it means to do good medical ethics. One such perennial issue is physician assistance in dying (PAD). This paper provides an account of the PAD debate in this journal over the last 40 years. It concludes that there is some (but limited) progress in the debate. The distinctions, analogies and hypothetical examples have proliferated, as have empirical studies, but very little has changed in terms of the basic arguments. The paper further argues that many of the contributions to the debate fail to engage fully with the concerns people have about the legal introduction of PAD in the healthcare system, perhaps because many of the contributions sit on the borderline between academic analysis and social activism. http://jme.bmj.com/content/41/1/40.abstract

- *PAIN & THERAPY* | Online – 12 December 2014 – **'Physician-assisted dying: Acceptance by physicians only for patients close to death.'** This study reports on German physicians' views on legalization of euthanasia and physician-assisted suicide, comparing this with a similar survey of U.K. doctors. Similar to the U.K. study, about 30% of the physicians surveyed support euthanasia in case of terminal illness and more support physician-assisted suicide. In contrast, in both countries, a great majority of physicians oppose medical involvement in hastening death in non-terminal illnesses. http://link.springer.com/article/10.1007/s40122-014-0029-z#

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