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

A sophisticated and "non-modern" ... form of medical care: Scroll down to <u>Specialist Publications</u> and 'Slowing down medicine: The plural worlds of hospice care' (p.8), in *Anthropology & Aging*.

Canada

Canadian Medical Association survey finds few doctors primarily focus on palliative care

ONTARIO | Northern Life (Sudbury) - 29 May 2015 – For the majority of physicians who provide palliative medicine services, it is not their primary field of practice...¹ In the largest survey of its kind performed in Canada, the association gathered responses from 1,114 physicians who deliver palliative care [PC] services. The survey found for 84% of respondents, PC was not their primary field of practice. Primary care providers need more support for PC education and training. Primary care has been the focus of PC programs in the hope many family physicians will provide the basic day-to-day symptom management required. Family physicians with a focused practice in palliative medicine and palliative medicine specialists - 16% of respondents - reported working an average of 36 hours per week in PC. Physicians who provide PC as part of their other clinical duties - 84% of respondents - reported working an average of seven hours providing PC services. The survey also examined the differences between rural and urban areas for access to PC services. Just 35% of palliative medicine physicians in rural and remote areas reported having specialized PC teams to provide care in their area,

compared to 79% of physicians in urban areas. Formal home health care for patients wishing to die at home was reported to be available by 49% of urban palliative medicine physicians versus 30% of rural physicians.<u>http://www.northernlife.ca/news/localN</u> <u>ews/2015/05/29-palliative-care-trainingdocs-sudbury.aspx</u>

Innovative palliative care delivery models hold keys to high-quality care

CANADIAN MEDICAL ASSOCIATION | Online – 27 May 2015 – A new Canadian Medical Association report presents a snapshot of where Canada stands now as well as what we will need to do as a nation to meet Canadians' increasing palliative care needs. A critical element of the report is how a national palliative care strategy would be a key component to an overall national seniors strategy, helping Canadians to get highquality care in their homes or elsewhere in the community rather than being hospitalized. https://www.cma.ca/Assets/assetslibrary/document/en/advocacy/palliative-carereport-online-e.pdf Noted in Media Watch, 12 May 2014, #357 (p.9):

 CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 2 May 2014 – 'CMA call for palliative care strategy gets federal backing.' The CMA and a Parliamentary All-Party Committee have joined forces to advocate for the development of a national strategy on palliative care. http://www.cma.ca/cmacallforpalliativecarestrategygetsfederalbacking

Canada to see a 40% increase in cancer patients by 2030: Report

THE GLOBE & MAIL | Online - 27 May 2015 - Canada's health-care system needs to brace itself for a major surge in cancer patients. The number of new cases of the disease diagnosed every year is expected to increase by 40% over the next 15 years, thanks largely to a rising tide of seniors, says a new report.¹ By 2030, an average of 277,000 new cancer cases are expected to be logged every year, up from nearly 200,000 this year and about 155,000 a decade ago, according to ... an annual summary of cancer figures and projections... This is the first time Canada's most prominent national cancer report has featured a longrange forecast ... The report comes a day after a separate study ... predicted British Columbia would see a 57% increase in cancer cases over a similar period for the same $reasons^2$ – the population is getting older and larger, and that means more cancer patients will be flooding Canada's hospitals. http://www.theglobeandmail.com/news/natio nal/canada-to-see-a-40-per-cent-increasein-cancer-patients-by-2030report/article24633729/

Extract from 'Canadian Cancer Statistics 2015'

With the rising incidence of cancer, there will be a commensurate increase in the need for diagnostic, treatment and support services, including palliative care in the healthcare system.

Extract from British Columbia Medical Journal

British Columbia needs to adequately prepare for a significant increase in demand for services related to cancer, including laboratory and diagnostic services, surgical and radiation treatment, systemic therapy, pain services, and palliative care.

Specialist Publications

'Impact of aggressive management and palliative care on cancer costs in the final month of life' (p.9), in *Cancer*.

- 'Canadian Cancer Statistics 2015: Predictions of the Future Burden of Cancer in Canada,' Canadian Cancer Society, Statistics Canada and the Public Health Agency of Canada. <u>https://www.cancer.ca/~/media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/Canadian-Cancer-Statistics-2015-EN.pdf</u>
- 2. 'Cancer incidence in British Columbia expected to grow by 57% from 2012 to 2030,' *British Columbia Medical Journal*, 2015;57(5):190-196. <u>http://bcmj.org/articles/cancer-incidence-british-</u> <u>columbia-expected-grow-57-2012-2030</u>

Specialist Publications

'Unanimity on death with dignity – legalizing physician-assisted dying in Canada' (p.13), in New England Journal of Medicine.

'From courtroom to bedside ... implications of *Carter v. Canada* and physician-assisted death' (p.13), in University of Ottawa Journal of Medicine.

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

Is it grief treatment, or handing out a "grief pill"?

OREGON | Oregon Public Broadcasting News (Portland) - 25 May 2015 - In 2012, a panel of psychiatrists working on the [5th edition of Diagnostic & Statistical Manual (DSM) of Mental Disorders voted to remove the "bereavement exclusion" from major depression diagnoses. The DSM guides psychiatrists, family care physicians and other prescribers of medicine in treating mental health conditions health. The "bereavement exclusion" kept doctors from diagnosing grieving patients with depression until at least two months passed following a death. That two month waiting period also kept doctors from prescribing anti-depressant medication to their patients. But now that the DSM has been changed, doctors can prescribe anti-depressants to patients during that time. Since this change to the DSM, there has been intense debate in mental health treatment circles about the use of anti-depressants in people who are grieving. One of the strongest voices against prescribing anti-depressants during this time frame

is Dr. Donna Schuurman, CEO of the Portland based ... National Center for Grieving Children & Families. Schuurman says prescribing antidepressants to bereaved patients amounts to giving them "grief pills." <u>http://www.opb.org/news/article/is-it-grief-</u> <u>treatment-or-handing-out-a-grief-pill-/</u>

Specialist Publications

'The antidepressant effect of hospice: Need for a more potent prescription' (p.10). in *JAMA Internal Medicine.*

'Research participation for bereaved family members: Experience and insights from a qualitative study' (p.11), in *Critical Care Medicine*.

'Association between hospice use and depressive symptoms in surviving spouses' (p.11), in *JAMA Internal Medicine*.

Noted in Media Watch, 24 November 2014, #385 (p.8):

 AMERICAN FAMILY PHYSICIAN, 2014;90(10):690-694. 'Grief and major Depression – Controversy over changes in DSM-5 diagnostic criteria.' One of the more controversial revisions is the elimination of the bereavement exclusion criterion for major depressive disorder, suggesting to some that grief is not a normal process. <u>http://www.aafp.org/afp/2014/1115/p690.html</u>

N.B. Additional articles on *DSM-5* noted in past issues of Media Watch are listed in the issues of the weekly report of 2 December 2013, #334 (p.10), 30 September 2013, #325 (p.12), and 13 May 2013, #305 (pp.4-5).

End-of-life care in Texas

Health Commission Bill could set up end-of-life ... debate

TEXAS | *The Texas Tribune* (Austin) – 23 May 2015 – Republican lawmakers have filed amendments to Senate Bill 200 that would limit medical professionals' abilities to override patients' advance directives or their families' wishes to continue life-sustaining treatment. The fight over endof-life care has been a perennial one at the [state] Legislature as lawmakers have struggled to decide whether families or medical professionals should make the final decision to end lifesustaining treatment for a terminally ill patient. Texas law allows physicians to discontinue treatment they deem unnecessary. But if a physician's decision to halt treatment is at odds with patients' advance directives – or if their families or surrogates disagree – patients or their families have 10 days to find an alternative medical provider. They can also appeal the doctor's decision to a hospital ethics committee. <u>https://www.texastribune.org/2015/05/23/health-commission-billcould-prompt-end-life-debat/</u>

Cont.

Noted in Media Watch, 23 March 2015, #402 (p.12):

WILLIAM & MARY JOURNAL OF WOMEN AND THE LAW | Online – 19 March 2015 – ""But I'm brain-dead and pregnant": Advance directive pregnancy exclusions and end-of-life wishes.' Marlise Muñoz was approximately 14 weeks pregnant when she suffered a pulmonary embolism, and two days later doctors declared her brain-dead. Knowing Marlise's end-of-life wishes, her husband ... asked her doctors to withdraw or withhold any "life-sustaining" medical treatment from his brain-dead wife. The hospital refused, and it relied on a Texas statute that automatically invalidates a woman's advance directive in the event she is pregnant. http://papers.sfm?abstract_id=2560306

Assisted (or facilitated) death

Representative sample of recent news media coverage:

CALIFORNIA | California Healthline – 29 May 2015 – 'California lawmakers take action on several health-related bills.' Bill SB 128 that would allow some dying patients to end their lives through lethal doses of medication. The move came after the California Medical Association dropped its opposition to the legislation. The bill would require: medication is self-administered; the patient is mentally competent; and, two physicians confirm the prognosis that the patient has six months or less to live. The measure now is headed for a full Senate vote. http://www.californiahealthline.org/articles/2015/5/29/calif-lawmakers-take-action-on--several-healthrelated-bills

Noted in Media Watch, 25 May 2015, #411 (p.4):

CALIFORNIA | ABC News – 20 May 2015 – 'California Medical Association changes aid-in-dying position.' The Association, which for decades has been against a law allowing physicians to help patients with terminal illnesses die, announced that it has become the first state medical association in the U.S. to change this position. http://abcnews.go.com/Health/california-medical-association-aid-dyingposition/story?id=31172740

International

Elderly face National Health Service discrimination under new UN death targets

U.K. | The Telegraph – 29 May 2015 – The National Health Service will be forced to discriminate against the over 70s to meet "highly unethical" UN health targets which seek to reduce premature deaths in younger people, senior medics have warned. Under the proposed Sustainable Development Goals. UN member states must cut the number of deaths from diseases like cancer. stroke. diabetes and dementia by one third by 2030. However because many are age-related illnesses people who succumb to those diseases from the age of 70 are not deemed to have died prematurely and so are not included in the target. In an open letter¹ ... an international group of ageing specialists say the new guideline sends out the message that health provision for younger groups must be prioritised at the expense of older people. Peter Lloyd-Sherlock, professor of social policy and international development at the University of East Anglia, and lead author of the letter, said: "This premature mortality target is highly unethical, since it unjustifiably discriminates against older people. The targets are not quite set in stone yet, so we have a final opportunity to impress upon the UN the need to alter this explicitly ageist health target. If this doesn't happen, people aged 70 and over will become second-class citizens as far as health policy is concerned." http://www.telegraph.co.uk/news/health/elder/11637179/Elderly-face-NHS-discrimination-undernew-UN-death-targets.html

1. 'A premature mortality target for the sustainable development goals for health is ageist,' *The Lancet*, 2015;385(9983):2147-2148. <u>http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)61016-9/abstract</u>

End-of-life care in Northern Ireland

Human rights issues raised in North's emergency departments

U.K. (Northern Ireland) | *The Irish Examiner* (Dublin) – 27 May 2015 – Concerns over care standards experienced by patients treated in the North's emergency departments have been flagged up by a human rights inquiry.¹ Instances of inadequate provision of pain relief, food and fluids were highlighted in an investigation by the Northern Ireland Human Rights Commission. The commission found individual cases of inhuman and degrading treatment, but had not uncovered evidence of "systemic violations" of human rights. While the inquiry reported many patient interactions with staff were positive, it noted at times care was under-

mined by a perceived disregard, lack of attention or kindness from health professionals.<u>http://www.irishexaminer.com/breakingne</u> ws/ireland/human-rights-issues-raised-innorths-emergency-departments-678946.html

Extract from *The Irish Examiner* report

One of the main issues of concern was the treatment experienced by some end-of-life patients and older patients, particularly those with dementia.

1. 'Human Rights Inquiry: Emergency Healthcare,' Northern Ireland Human Rights Commission, May 2015. <u>http://www.nihrc.org/uploads/publications/NIHRC_Emergency_Healthcare_Report_</u> <u>Stricty_Embargoed_until_27_May_2015_00.01hrs.pdf</u>

End-of-life care in Scotland

What is dying like? New info published by the National Health Service

U.K. (Scotland) | *The Herald* (Edinburgh) – 26 May 2015 – Health experts have issued new guidelines¹ explaining what happens when someone is dying amid concerns that death has become an alien experience for many of us. Shallow or rattly breathing, swelling hands and sleepiness are among the changes described in the official National Health Service Scotland guidance, which is being promoted in the belief that having some idea of what to expect in the last days and hours of a person's life can be reassuring. <u>http://www.heraldscotland.com/news/health/what-is-dying-like-new-info-published-by-the-nhs.126795738</u>

1. 'What is dying like?' National Health Service Scotland, May 2015. http://www.nhsinform.co.uk/palliativecare/deathandbereavement/whatisdyinglike



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

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.15.

End-of-life care in Australia

Patients kept alive for longer because doctors "don't know dying wishes"

AUSTRALIA (Victoria) | The Herald Sun (Melbourne) - 25 May 2015 - Terminal patients are being kept alive with unwanted and unnecessary life-prolonging treatments because doctors do not know what their final wishes are, research reveals. The research also shows one in seven Australian physicians report seeing patients continuing to receive treatments on a weekly basis to keep them alive, which may be contrary to their wishes, leading to calls for an overhaul of end-of-life care in Australia. While the euthanasia debate continues to rage in Australia, a Royal Australasian College of Physicians survey of more than 15,000 doctors reveals a much greater problem impacting many times more Australians because doctors do not routinely discuss treatment options with their patients. Eight out of 10 doctors believe physicians do not know what their patient's wishes are nearing the end of their life. The report ... calls for doctors to be better trained to document a patient's wishes for such things as life-support treatments, hospitalisation and where they would like to die.http://www.heraldsun.com.au/news/victor ia/patients-kept-alive-for-longer-becausedoctors-dont-know-dying-wishes/storyfni0fit3-1227367198964

End-of-life care in Queensland

Strategy for end-of-life care launched

AUSTRALIA (Queensland) | My Sunshine Coast (Cotton Tree) - 26 May 2015 - Minister for Health Cameron Dick ... launched Queensland's state-wide strategy for end-of-life care, which will ensure people and their families confronting a terminal illness receive the high standard of care they deserve.¹ Mr. Dick simultaneously launched the Queensland Clinical Senate's Charter for care of adult patients at the end of life ... to further educate health professionals on how to recognise the care needs of terminally ill patients.² These will provide platforms for people nearing the end of their life, their families, carers and healthcare workers to talk about a patient's wishes. Local healthcare providers will have the freedom to drive local implementation of the strategy. http://mysunshinecoast.com.au/news/newsdisplay/strategy-for-end-of-life-carelaunched.38559

1. 'Statewide Strategy for End-of-Life Care,' Department of Health, Queensland Government, May 2015. <u>http://www.health.gld.gov.au/publications/portal/healthstrategies/end-of-life-strategy-full.pdf</u>

2. 'A Charter for Care of Adult Patients at the End of Life,' Health Consumers Queensland, May 2015. http://www.health.gld.gov.au/publications/clinicalpractice/engagement/gcs-patient-charter.pdf

Of related interest:

- AUSTRALIA | ABC News (Brisbane) 29 May 2015 'What does a national approach to palliative care look like?' Today Health Ministers across Australia have endorsed a national approach to end-of-life care in hospitals. <u>http://blogs.abc.net.au/queensland/2015/05/what-does-anational-approach-to-palliative-care-look-like.html</u>
- AUSTRALIAN COMMISSION ON SAFETY & QUALITY IN HEALTH CARE | Online 28 May 2015 – 'Health Ministers endorse new approach to end-of-life care in hospitals.' A new consensus statement describing the essential elements for providing safe and high-quality care at the end of life has been endorsed by the Australian Health Ministers as the national approach to the delivery of end-of-life care in Australian hospitals. <u>http://www.safetyandquality.gov.au/wpcontent/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-highquality-end-of-life-care.pdf
 </u>

Prison Hospice Backgrounder



End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. An updated compilation of the articles, reports, etc., noted in past issues of the weekly report, is available on the Palliative Care Community Network website at: <u>http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons</u>

End-of-life care in New Zealand

Call for more health funding for rural areas

NEW ZEALAND | Radio New Zealand (Wellington) – 25 May 2015 – A body representing the health sector in rural New Zealand is calling on the Government to make sure the funding boost from this year's budget reaches rural communities. The Government announced an injection of \$76 million to help hospices expand their care services and create 60 new nurse, education and support roles. Rural General Practice Network's chief executive Dalton Kelly said he had hoped the budget would offer more for rural communities because of their vulnerability, caused by distance, and the time it takes for services to be accessed. "Over 600,000 New Zealanders live in rural New Zealand and they're entitled to a health service that is as good as any where in the urban area." Mr. Kelly said no matter where in the country they were, those who are terminally ill should be able to access palliative care. http://www.radionz.co.nz/news/rural/274509/call-for-more-health-funding-for-rural-areas

Noted in Media Watch, 25 May 2015, #411 (p.5):

NEW ZEALAND | Scoop (Wellington) – 21 May 2015 – '\$76.1 million more for palliative care and hospices.' The Government announced the additional investment over four years to support hospices during the election campaign last year. From 1 July 2015, \$13 million is being allocated each year to help hospices expand their community palliative care services so they can better support terminally ill people at home and in aged-care facilities. An additional \$3.1 million in 2015/2016, rising to \$7 million from 2016/2017, will support the recruitment of nurse specialists, palliative care educators... <u>http://www.scoop.co.nz/stories/PA1505/S00328/761m-more-forpalliative-care-and-hospices.htm</u>

N.B. New Zealand was rated 3rd (of the 40 countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, published by the Economist Intelligence Unit, 2010. http://graphics.eiu.com/upload/QOD main final edition Jul12 toprint.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

U.K. (Scotland) | STV News (Glasgow) - 24 May 2015 -'Survey finds support for proposals to legalise assisted suicide.' Almost three-quarters of adults support proposals to legalise assisted suicide in principle, according to a new poll... MSPs [Members of the Scottish Parliament] will debate and vote on the general principles of the Assisted Suicide Bill when it comes before Holyrood [the Scottish parliament] ... The Bill, first brought forward by independent MSP Margo Mac-Donald, who died after a battle with Parkinson's disease in 2014, would allow those with terminal or lifeshortening illnesses to obtain help in ending their suffering. A survey by ORB International on behalf of CARE (Christian Action Research & Education) for Scotland revealed 35% of Scots agree strongly with the principle of assisted suicide while 38% agree, a further 7% disagree strongly and 8% disagree. The poll ... also asked respondents who support the measure about whether the arguments against the proposals to legalise assisted suicide would make them change their minds. Arguments against the proposal include the risk people will feel pressurised into ending their life early so as not to be a financial or care burden on loved ones. http://news.stv.tv/scotland-decides/news/1321433survey-finds-support-for-proposals-to-legalise-assistedsuicide/

Scottish parliament rejects assisted dying law

U.K. (Scotland) | *The Guardian* (London) – 27 May 2015 – In a free vote, MSPs voted 82-36 against a bill that proposed those with terminal illnesses could seek help of a doctor to end their lives, after a deeply personal debate. http://www.theguardian.co m/society/2015/may/27/sc ottish-parliament-rejectsassisted-suicide-law

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

Education intervention "Caregivers Like Me" for Latino family caregivers improved attitudes toward professional assistance at end-of-life care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 27 May 2015 – This study explores the ability of a culturally sensitive and case-based education intervention ... to improve knowledge and attitudes regarding end-of-life (EOL) resources among Latino caregivers. Participants were mostly females (79%) with mean age of 56 ± 15 years. They reported active learning from intervention (91%) and high satisfaction (92%) with educational experience. Both caregiver stress self-awareness and willingness to accept professional help improved significantly from pre-test to post-test. A culturally sensitive educational intervention increased Latino caregivers' self-awareness about caregiver stress and the need to consider professional assistance for EOL care. http://ajh.sagepub.com/content/early/2015/05/26/1049909115584315.abstract

Noted in Media Watch, 17 March 2014, #349 (p.7):

 AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 12 March 2014 – 'Evaluation of hospice care by family members of Hispanic and non-Hispanic patients.' Caregivers of Hispanic patients were more likely to report hospice was inconsistent with the patient's wishes, and they received more attention than desired for emotional issues. Caregivers of Hispanic patients were also more likely to express that emotional/spiritual forms of support were insufficient. <u>http://ajh.sagepub.com/content/early/2014/03/11/1049909114526969.abstract</u>

Noted in Media Watch, 7 October 2013, #326 (p.3):

 U.S. (California) | New America Media – 2 October 2013 – 'Why are Latinos not using palliative and hospice care?' Without change, aging Latinos are reaching the end of their lives unprepared spiritually or financially. Experts believe that the shift needs to happen from within the community, while others say it is a matter of poor cultural sensitivity from service providers. http://newamericamedia.org/2013/10/why-are-latinos-not-using-palliative-and-hospice-care.php

N.B. Scroll down to 'Caregivers' three-cornered hats...' (p.12), in *Palliative Medicine*. Additional articles on America's Latino population and end-of-life care noted in past issues of Media Watch are listed in the issue of the weekly report of 29 July 2013, #316 (p.13).

Slowing down medicine: The plural worlds of hospice care

ANTHROPOLOGY & AGING, 2015;36(1):45-61. This ethnography reflects on a non-profit hospice care organization in the Midwestern U.S. where caregivers "slow down" medical care by acknowledging the plurality of forces that constitute the illness experience, philosophically departing from their biomedical, non-hospice counterparts. It demonstrates the ontological effect of "slowing down" and attending to a set of patient problems that extends beyond the biological, or any distinct, domain. The result is a medical world that privileges the embodied, lived expression of disease – rather than the statistical, clinical expression – resulting in medical care that is enmeshed in the variables of everyday life. I therefore situate hospice care in a historical moment witnessing the emergence of a sophisticated and "non-modern" ... form of medical care. http://anthro-age/article/view/64

Noted in Media Watch, 25 February 2013, #294 (p.2):

U.S. (New Hampshire) | The Keene Sentinel – 24 February 2013 – 'Slow medicine could have benefits.' Slow medicine allows a patient to decide that he or she does not want to experience the impact of a possible procedure or course of treatment. This decision does not mean treatment for other conditions will also be withheld. Nor is slow medicine a variety of hospice care, though there are similarities. Palliative care, to ease the symptoms of the condition, is a component of slow medicine. Much has been learned from the experience of the hospice movement. http://www.sentinelsource.com/opinion/columnists/staff/bauman/slow-medicine-could-have-benefits-wit-and-wisdom-by-martha/article_cf9698c1-e6bb-5815-ad8d-ff5c9361af6d.html

Worsening disability in older people: A trigger for palliative care

BRITISH MEDICAL JOURNAL | Online - 20 May 2015 - Earlier identification of older patients at risk of deteriorating must become routine clinical practice in hospitals and primary care. Identification should trigger conversations about what patients know about their health problems, what they are expecting, and what is important to them. Finding out about people's goals helps patients, families, and health professionals to talk about possible treatment and care options aligned with those goals and to make individualised plans for current and future care. Some people will choose to make an advance care plan, nominating a legally appointed healthcare proxy and/or specifying treatments they would refuse if their health were to deteriorate and they lacked decision making capacity. All patients at risk of deteriorating, and their families, should be invited to discuss the benefits of anticipatory care planning, which can include their general and specific goals and an agreed emergency care plan should their health, functional ability, or care needs change suddenly. Effective systems to record and share advance and anticipatory care plans for people at risk are important, along with more responsive emergency care. National Health Service Scotland has an established, national electronic anticipatory care plan (Key Information Summary) accessible to primary care, secondary care, and emergency services, and similar systems are becoming increasingly common. http://www.bmj.com/content/350/bmj.h2439

End-of-life care in Canada

Impact of aggressive management and palliative care on cancer costs in the final month of life

CANCER | Online – 29 May 2015 – Cancer patients who receive aggressive end-of-life care incur 43% higher costs than those managed non-aggressively. Palliative consultation may partially offset these costs and offer resultant savings. This study used population data to identify a cohort of patients who died of cancer in Ontario, Canada (2005-2009). Individuals were categorized as having received or having not received aggressive end-of-life care according to quality measures related to acute institutional care or chemotherapy administration in the end-of-life period. Costs (2009 Canadian dollars) were collected over the last month of life through the linkage of health system administrative databases. Among 107,253 patients, the mean per-patient cost over the final month was \$18,131 for patients receiving aggressive care and \$12,678 for patients receiving nonaggressive care. Patients who received chemotherapy in the last 2 weeks of life also sustained higher costs than those who did not. For individuals receiving end-of-life care in the highest cost quintile, early and repeated palliative care consultation was associated with reduced mean per-patient costs. In a multivariate analysis, chemotherapy in the 2 weeks of life remained predictive of increased costs, whereas access to palliation remained predictive for lower costs. http://onlinelibrary.wiley.com/doi/10.1002/cncr.29485/pdf

Of related interest:

JOURNAL OF CLINICAL NURSING | Online – 23 May 2015 – "Rapid discharge": Issues for hospital-based nurses in discharging cancer patients home to die.' Nurses experience challenges in discharging imminently dying cancer patients home, due to time limitations and complex needs of patients and their families. [In this study] issues in facilitating rapid discharge fell into three categories: 1) time; 2) discharge processes; and, 3) family preparation. Decisions to die at home appeared solely family/patient driven and made when death appeared imminent. Discharge then became time-critical, as nurses needed to complete multiple tasks within short timeframes. Stress was exacerbated by nurses' inexperience and the infrequent occurrence of rapid discharge, as well as absence of standardised discharge framework for guidance. http://onlinelibrary.wiley.com/doi/10.1111/jocn.12872/abstract;jsessionid=2D3CF8CD8E0922EB DB10A620447120A3.f03t03?deniedAccessCustomisedMessage=&userlsAuthenticated=false

Does current pre-hospital care for patients at the end of their life reflect best practice guidance

EMERGENCY MEDICINE JOURNAL, 2015;32(6):e13. The end-of-life care good practice guide encourages organisations to enable terminally ill patients to be cared for and die outside of hospital. Ambulance services play a critical role in achieving this goal, however little guidance exists for ambulance crews. Only 4% of patients had out-of-hours information registered with the ambulance service; 48% were attended out-of-hours and their wishes were unknown; 38% of crews consulted with the patients' GP/palliative care team to determine whether the patient had a plan for their end of life; 88% of patients were conveyed (27% to a hospice and 73% to Accident & Emergency – A&E); 53% of survey respondents were not confident treating this patient group. Respondent [to the survey] identified training needs, specifically on: alternative care pathways, evidence of terminal illness, and Do Not Attempt CPR orders. Pain and discomfort was considered for 83% of patients, with subsequent action taken for 73%. Patients' wishes were not documented for 79%, however the patient's diagnosis and prognosis was clear for 97%. Referrals to A&E, a hospice or to the patient's GP/palliative care team were felt to be appropriate to the patient's presenting complaint for 93%. http://emj.bmj.com/content/32/6/e13.2.abstract

Noted in Media Watch, 6 April 2015, #404 (p.9):

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 27 March 2015 – "'We are strangers walking into their life-changing event": How pre-hospital providers manage emergency calls at the end of life.' Emergency 911 calls are often made when the end stage of an advanced illness is accompanied by alarming symptoms and substantial anxiety for family caregivers, particularly when an approaching death is not anticipated. How paramedics and emergency medical technicians manage emergency calls near death influences how and where people will die, if their end-of-life choices are upheld and how appropriately health care resources are utilized. http://www.jpsmjournal.com/article/S0885-3924(15)00149-9/abstract

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/cgibin/go.pl/library/article.html?uid=102856;article=IJPN 20 1 37 44

The antidepressant effect of hospice: Need for a more potent prescription

JAMA INTERNAL MEDICINE | Online – 26 May 2015 – Although caring for a terminally ill spouse can be gratifying, it can also be depressing. Research has shown that caregiving poses risks to a spouse's mental health both before and after the ill spouse dies. Depending on the circumstances of the death, psychological distress may increase or decrease as the surviving spouse transitions from caregiver to widow or widower. Important environmental factors external to the caregiver may contribute to a widowed person's bereavement adjustment. One such environmental factor is the end-of-life care that the patient receives. For example, research has shown that the rate of major depressive disorder increases significantly among bereaved caregivers following deaths that involve aggressive life-prolonging care compared with deaths that do not involve such care. Given caregivers' heightened vulnerability to psychological distress and their expanding role in the provision of care for terminally ill patients, there is a human, clinical, and public health interest in determining ways in which end-of-life care might improve the mental health of spousal caregivers. http://archinte.jamanetwork.com/article.aspx?articleid=2296007

Cont.

Of related interest:

- CRITICAL CARE MEDICINE | Online 22 May 2015 'Research participation for bereaved family members: Experience and insights from a qualitative study.' Bereavement research is possible after loss of a loved one in the ICU and may even be beneficial for family members. Exploring families' experiences of research participation helps define specific family needs in this setting. They need opportunities to voice their feelings about their experience in the ICU and to give meaning to the end-of-life process; families also need to feel they are still cared for. http://journals.lww.com/ccmjournal/Abstract/publishahead/Research Participation for Bereaved d Family.97251.aspx
- JAMA INTERNAL MEDICINE | Online 26 May 2015 'Association between hospice use and depressive symptoms in surviving spouses.' Family caregivers of individuals with serious illness are at risk for depressive symptoms and depression. Hospice includes the provision of support services, yet evidence is limited regarding the effect of hospice use on depressive symptoms among surviving caregivers. After bereavement, depression symptoms increased overall for surviving spouses [i.e., study participants] regardless of hospice use. A modest reduction in depressive symptoms was more likely among spouses of hospice users than among spouses of non-hospice users. <u>http://archinte.jamanetwork.com/article.aspx?articleid=2296014</u>

Palliative care medical education in European universities: A descriptive study and numerical scoring system proposal for assessing educational development

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 26 May 2015 – A number of international institutions have called for its implementation within undergraduate medical curricula. Forty-three countries (81%) provided the requested information. In 13 countries (30%), a PM course is taught in all medical schools, being compulsory in six of them (14%). In 15 countries (35%), PM is taught in at least one university. In 14 countries (33%), PM is not taught within medical curricula. A full professor of PM was identified in 40% of countries. Three indicators were developed to construct a scale of educational development: 1) proportion of medical schools that teach PM; 2) proportion of medical schools that offer PM as a compulsory subject; 3) total number of PM professors. The highest level of PM educational development was found in Israel, Norway, the U.K., Belgium, France, Austria, Germany and Ireland. PM is taught in a substantial number of undergraduate medical programs at European universities and a qualified teaching structure is emerging; however, there is a wide variation in the level of PM educational development between individual countries. <u>http://www.jpsmjournal.com/article/S0885-3924(15)00241-9/abstract</u>

Recommendations to surrogates at the end of life: A critical narrative review of the empirical literature and a normative analysis

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 26 May 2015 – Physician recommendations have historically been a part of shared decision making. Recent literature has challenged the idea that physician recommendations should be part of shared decision making at the end of life, particularly the making of recommendations to surrogates of incapacitated patients. Close examination of the studies and the available data on surrogate preferences for decisional authority at the end of life, however, provide an empirical foundation for a style of shared decision making that includes a physician recommendations. Moreover, there are independent ethical reasons for arguing that physician recommendations enhance rather than detract from shared decision making. <u>http://www.jpsmjournal.com/article/S0885-3924(15)00246-8/abstract</u>

Back Issues of Media Watch

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: <u>http://www.ipcrc.net/archive-global-palliative-care-news.php</u>

Caregivers' three-cornered hats...

PALLIATIVE MEDICINE, 2015;29(6):485-486. For some time it has been recognised that caregivers may have many roles that are, at best, ambiguous and, at worst, contradictory. The first two corners of caregivers' hats are characterised as being co-workers and care recipients. (Isn't it interesting that in the health literature it is family and friends who are deemed to be "co-workers" of health professionals not the other way around? In fact, health professionals may be fortunate enough to be co-workers with family and friends providing care for people at the end of life.) One of the articles in this issue of *Palliative Medicine*¹ highlights that health professionals are considered by caregivers to be "helpful and hindering [family caregivers] in meeting the challenges that they face." But there is a third corner of the hat that needs to be acknowledged for caregivers – healthcare recipients (patients) in their own right. It is imperative that all three roles are assessed and supported if hospice/palliative care services are going to optimise outcomes for caregivers of people with life-limiting illnesses. After all, caregivers need to be in the best possible health for the role that they have, and hospice/palliative care services have a duty of care to ensure as caregivers complete their roles that they are in the best possible health to move on with their lives. <u>http://pmj.sagepub.com/content/29/6/485.full.pdf+html</u>

 "You only have one chance to get it right": A qualitative study of relatives' experiences of caring at home for a family member with terminal cancer,' *Palliative Medicine*, 29 January 2015. A qualitative study using semi-structured interviews. [Noted in Media Watch, 2 February 2015, #395 (p.12)] <u>http://pmj.sagepub.com/content/early/2015/01/29/0269216314566840.abstract</u>

Noted in Media Watch, 14 February 2011, #188 (p.11, under 'Worth Repeating'):

 CANADIAN JOURNAL OF PSYCHIATRY, 2004;49(6):359-365. 'Palliative care for families: Remembering the hidden patients.' The authors describe the impact of a terminal illness on the family in terms of family members' health, family communication issues, psychological issues, needs for information, physical care demands, and family costs of caring. https://ww1.cpaapc.org/Publications/Archives/CJP/2004/june/kristjanson.pdf

End-of-life care in Italy

Early palliative care

RECENTI PRORESSI IN MEDICINA, 2015;106(5):201-202. Early palliative care is a intervention model that is increasingly used for patients with advanced chronic degenerative conditions. It has been shown to be effective in improving patients' quality of life and disease awareness and providing guidance and support in deciding on treatment choices, with significant cost savings for the healthcare system due to increased appropriateness of care. Several randomized controlled trials have demonstrated the efficacy of early palliative care, in particular in cancer patients and, more recently, also in patients with other advanced life-threatening illnesses. Results have been consistent in showing that early palliative care improves quality of life without negatively affecting survival compared with more aggressive treatment options. Palliative care should be delivered through an integrated approach to care that recognizes the roles of both general practitioners and hospital-based specialists for the early identification of patients who may most benefit from this intervention. http://www.recentiprogressi.it/articoli.php?archivio=yes&vol_id=1868&id=20400

N.B. Italian language article.

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

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

Cont.

Noted in Media Watch, 10 June 2013, #309 (p.14):

 FUTURE ONCOLOGY, 2013;9(6):771-776. 'Improving the quality of life of terminally ill oncological patients: The example of palliative care at Hospice Villa Speranza.' Hospice Villa Speranza (HVS) is a National Health System-accredited facility of the Università Cattolica del Sacro Cuore (Rome), which has been providing palliative care for patients since 2000, both as hospice and home care. <u>http://www.futuremedicine.com/doi/pdf/10.2217/fon.13.59</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- HUMAN RIGHTS LAW REVIEW | Online 16 May 2015 'Whose right to what life? Assisted suicide and the right to life as a fundamental right.' This article discusses the way in which the right to life, as a core human right and one of the most fundamental elements of the European Convention on Human Rights, values life and is founded on individual life. It is interpreted by the European Court of Human Rights as the right not to be killed, but in cases of (assisted) suicide it is, furthermore, invoked to oppose the right to self-determination. This article targets this use of the right to life in arguments against assisted suicide, arguing that if the right to life in a sense external to that individual, and hence can only be considered an individual right if attributed to an abstract subject beyond the empirical individual. This calls its fundamentality in question, and leaves the rights-based argument against assisted suicide in difficulty. http://hrlr.oxfordjournals.org/content/early/2015/05/16/hrlr.ngv006.abstract
- NEW ENGLAND JOURNAL OF MEDICINE, 2015;372(22):2080-2082. 'Unanimity on death with dignity legalizing physician-assisted dying in Canada.' In February 2015, Canada legalized physician-assisted dying a first among countries with common-law systems, in which law is often developed by judges through case decisions and precedent. The Supreme Court of Canada issued the decision in *Carter v. Canada*, and its reasoning and implications for clinical practice bear examination. Canada's path to this point has not been short. In 1993, the Court rejected legalization of physician-assisted dying on a 5-to-4 vote, and Parliament has since considered the issue several times but demurred though the province of Quebec passed a "medical aid in dying" law in 2014. The Carter judgment triggered a year-long grace period during which Canada's federal and provincial governments and the medical profession must arrange for an orderly transition so that by early 2016, Canadian patients can choose to die with a doctor's help. http://www.nejm.org/doi/full/10.1056/NEJMp1502442
- SWISS MEDICAL NEWS | Online 21 May 2015 'Swiss physicians' attitudes to assisted suicide.' The vast majority of physicians surveyed consider assisted suicide to be justifiable in principle, however, their support is strongly dependent on the specific clinical situation. The study indicates that even physicians expressing a potential readiness to perform assisted suicide themselves would not do so automatically if all the criteria for assisted suicide were met. Assisted suicide thus appears to be an exceptional situation, which physicians would only do on a voluntary basis. The authors recommend that the current Swiss Academy of Medical Sciences (SAMS) Guidelines regulating physician-assisted suicide in Switzerland should be reviewed with regard to the end-of-life criterion as a necessary condition for physician-assisted suicide. http://www.smw.ch/scripts/stream.pdf.php?doi=smw-2015-14142
- UNIVERSITY OF OTTAWA JOURNAL OF MEDICINE, 2015;5(1):1-3. 'From courtroom to bedside ... implications of Carter v. Canada and physician-assisted death.' On 6 February 2015, the Supreme Court of Canada concluded that "the prohibition on physician-assisted dying is void insofar as it deprives a competent adult of such assistance where 1) the person affected clearly consents to the termination of life; and, 2) the person has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition." The Court added, "The declaration of invalidity is suspended for 12 months," to allow the government to respond with appropriate legislation to guide and regulate the practice of physician-assisted Death. https://uottawa.scholarsportal.info/ojs/index.php/uojm-jmuo/article/view/1276

Worth Repeating

Communication about end-of-life care between language-discordant patients and clinicians: Insights from medical interpreters

JOURNAL OF PALLIATIVE MEDICINE, 2005;8(5):1016-1024. Communication about health care and especially end-of-life care is difficult for clinicians and patients when they do not speak the same language. The authors developed three frameworks for understanding high-quality language-discordant communication about end-of-life care. The first addresses physician and interpreter professionalism, including humanistic qualities and emotional support capabilities important for high quality care. The second is physician-centered and highlights communication skills, as well as coordination with other providers and cultural sensitivity. The third is interpreter-centered, focusing on role conflicts, including struggles concerning expectations to provide strict interpretation versus being a cultural broker. Interpreters' recommendations for improving quality of this care include pre-meetings with interpreters before encounters involving delivery of bad news and explicit discussions with interpreter about whether the clinician expects strict interpretation or cultural brokering. Interpreter recommendations provide physicians and health care organizations with specific tools that may improve quality of communication about end-of-life discussions. http://online.liebertpub.com/doi/abs/10.1089/jpm.2005.8.1016

Media Watch: Editorial Practice

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

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Something Missed or Overlooked?

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

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <u>http://hospicecare.com/about-iahpc/newsletter/2015/05/media-watch/</u>

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

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

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

Asia

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

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

Australia

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

Canada

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

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

Europe

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

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

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

Barry R. Ashpole Guelph, Ontario CANADA 'phone: 519.837.8936 e-mail: <u>barryashpole@bell.net</u>