Media Watch...

is intended as an advocacy and research 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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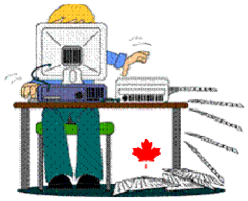

Compiled & Annotated by Barry R. Ashpole

Integration of palliative care in emergency medicine: Scroll down to Specialist Publications and 'Demonstrations of clinical initiatives to improve palliative care in the emergency department: A report from the IPAL-EM initiative' (p.8), in *Annals of Emergency Medicine.*

Canada

We need hospice funding

BRITISH COLUMBIA | *Comox Valley Echo* (Courtenay) – 5 April 2013 – It's not simply the Comox Valley Hospice Society asking where funding is for hospice care here.[1] It's those of us who live and die here and our families! I only have to walk down the street to see how we have increasingly become a retirement community with more and more of us who will need care, as we are all going to die someday. Now I read about the millions of dollars pouring in to these services in the lower mainland where they already have hospices and much more available care.[2] I keep hearing at the Vancouver Island Health Authority meetings how there is a plan for these services for those of us in the Comox Valley. Then there's another revised plan, and the years go by. It seems like we are way past the time to keep planning. I know I for one don't want to die in a ward in the hospital, nor do I want to burden my family to be my day and night caregiver when I reach that point. Being the caregiver in the final days in an imminent home death does not allow you to spend quality time with your loved one, there is too much to do to keep them comfortable. And then it is over, family and friends return to their lives and you need help handling your grief, We need hospice! Whether it's the Ministry of Health or our health authority, they need to start funding care here in our community! Nothing will happen until they stop talking and start doing. http://www.canada.com/need+hospice+funding/8199016/story.html

1. 'Comox Valley wonders where its end-of-life funding is,' *Comox Valley Record* (Courtenay), 27 March 2013. Where's the funding for end-of-life care in the Comox Valley? The Comox Valley Hospice Society has been asking this question for years, but after the Health Ministry's announcement this week of millions for hospice care in the Lower Mainland, the society is asking the question with renewed vigour. Residents have been advocating for residential hospice beds for over six years, yet there are still zero dedicated hospice palliative care beds. [Noted in Media Watch, 1 April 2013] http://www.comoxvalleyrecord.com/news/200335711.html

2. 'Province introduces plan to improve end-of-life care,' 1130 Radio News (Vancouver), 25 March 2013. Dying-with-dignity is the goal of a new plan by the province to improve end-of-life care. [Noted in Media Watch, 1 April 2013] http://www.news1130.com/2013/03/25/bc-introduces-plan-to-improve-end-of-life-care/

Provinces need to follow through on home care funding commitments: Report

CTV NEWS | Online – 4 April 2013 – Canada's provinces and territories talk a good game when it comes to funding in-home health care, but a new report is urging all orders of government to put their money where their mouths are.[1] The Canadian Home Care Association has released a study that found that while most provinces have emphasized the need to step up funding for care provided outside of hospitals, none have followed through on their verbal commitments. The report calculated the average amount per capita spent on health care based on budgets from all 10 provinces and three territories. The association found that of the $3,957 spent on each person in 2010, only $159 or four per cent was earmarked for home care. Those levels have remained fairly stable over the past five years, Association Executive Director Nadine Henningsen said, adding some provinces have even reduced overall home care funding. Henningsen said the same story has played out in Ottawa where the federal government shoulders responsibility for offering health coverage to First Nations Canadians, veterans, RCMP employees and members of the Department of National Defence. Henningsen said those programs could not be directly compared to provincial offerings, but said a funding shortfall for home care was equally evident. The overall trend, she said, is a home care budget that doesn't live up to expectations. http://www.ctvnews.ca/canada/provinces-need-to-follow-through-on-home-care-funding-commitments-report-1.1223641

1. 'Portraits of Home Care,' Canadian Home Care Association, April 2013. http://www.cdnhomecare.ca/media.php?mid=3394

Noted in Media Watch, 14 January 2013:

- *SOCIAL SCIENCE & MEDICINE* | Online – 5 January 2013 – **'The fiscal impact of informal caregiving to home care recipients in Canada: How the intensity of care influences costs and benefits to government.'** The authors conducted a cost-benefit analysis where they considered the costs of unpaid caregiving to be potential losses in income tax revenues and changes in social assistance payments and the potential benefit of reduced paid care expenditures. At the lowest intensities of caregiving, there was a net benefit to government from caregiving, at both the individual and population levels. At the population level, the net benefit to government was estimated to be $4.4 billion for caregivers providing less than five hours of weekly care. At the highest intensity of caregiving, there was a net cost to government of $641 million. http://www.sciencedirect.com/science/article/pii/S0277953612008386

End-of-life talks lacking between doctors, patients

REUTERS | Online – 1 April 2013 – Although many older patients in Canada have thought about end-of-life care and discussed it with family members, a new study suggests, fewer have spoken with doctors and had their wishes noted accurately in their medical record.[1] Many elderly people prefer to die at home instead of in the hospital – but that's not always the way it works out. Dr. Daren Heyland from Kingston General Hospital in Ontario said a lack of discussion about patients' wishes is often what leads to very aggressive care at the end of life, followed by stress and regret from family members. "These are 80-year-old patients who are frail, sick, in hospitals, and so they've obviously considered their end-of-life situation," Heyland, who led the new study, told Reuters Health. "The real problem is the failure of the health care team to engage them." http://www.reuters.com/article/2013/04/01/us-health-end-of-life-talks-idUSBRE9300IO20130401

1. 'Failure to engage hospitalized elderly patients and their families in advance care planning,' *JAMA Internal Medicine*, 1 April 2013. Many elderly patients at high risk of dying and their family members have expressed preferences for medical treatments at the end of life. However, communication with health care professionals and documentation of these preferences remains inadequate. http://archinte.jamanetwork.com/article.aspx?articleid=1673746

   N.B. Comment on 'Failure to engage hospitalized elderly patients and their families in advance care planning.' http://archinte.jamanetwork.com/article.aspx?articleid=1673748

Cont.

Noted in Media Watch, 9 April 2012:

- BRITISH COLUMBIA | *The Vancouver Sun* – 4 April 2012 – **'Few Canadians plan for life's final days: Poll.'** In an Ipsos-Reid poll of 1,000 Canadians, 86% of respondents said they were not aware of what advance care planning was. Dr. Daren Heyland ... says a lack of care planning can cause a worsened experience during the months leading towards death. http://www.vancouversun.com/health/Canadians+plan+life+final+days+Poll/6412086/story.html

Why obituaries seduce us: They're a door on a world that's vanishing

THE GLOBE & MAIL | Online – 5 April 2013 – When the flamboyant British publican Kim de la Taste Tickell died in 1990 at 73, his obituary in *The Daily Telegraph* noted his fastidious criteria for selecting clientele: "'I'm not having south London garage proprietors and their tarts in here,' he would screech at startled patrons. 'Out! Out! Out!'" Most readers probably felt they knew Mr. Tickell from that sentence alone, but the obituary went on to reveal that the Tickell Arms served the *jeunesse dorée* of Cambridge University, that its proprietor wore silver-buckled shoes and that he was sometimes known as "the Basil Fawlty of the Fens." The good that men do may be interred with their bones, as Shakespeare wrote – but the best bits live on after them, thanks to the obituary pages. http://www.theglobeandmail.com/commentary/why-obituaries-seduce-us-theyre-a-door-on-a-world-thats-vanishing/article10823791/

U.S.A.

As palliative care need grows, specialists are scarce

NATIONAL PUBLIC RADIO | Online – 4 April 2013 – Baby boomers have never needed more care to ease their pain and suffering. But there simply aren't enough specialists to get the job done. There's a shortfall of as many as 18,000 physicians focused on palliative care and hospice care. Right now, there are 5,150 hospice programs and 1,635 hospital palliative care teams in the U.S., according to the American Academy of Hospice & Palliative Medicine. That means there's only one specialist for every 20,000 older adults living with a severe chronic illness. "There have to be more people for whom this is a specialty," says Dr. Thomas Smith, director of palliative medicine at Johns Hopkins Hospital in Baltimore. "If you don't have enough people to be out there practicing and showing people a better way to communicate, a better way to relieve pain, a better way to help people's distress, it won't happen." Patients with many kinds of illness – from chronic to life-ending – can turn to palliative care for help with symptoms. The specialty also spans psychological counseling, help with family conflicts and spiritual support. http://www.npr.org/blogs/health/2013/04/03/176121044/as-palliative-care-need-grows-specialists-are-scarce

Noted in Media Watch, 27 August 2012:

- *AMERICAN MEDICAL NEWS* | Online – 21 August 2012 – **'More doctors sought to meet hospice and palliative care demands.'** The U.S. physician work force is failing to keep pace with increasing demands for hospice and palliative care services as more people live longer with chronic diseases, said the American Academy of Hospice & Palliative Medicine. http://www.ama-assn.org/amednews/2012/08/20/prsc0821.htm

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

Dementia care cost is projected to double by 2040

THE NEW YORK TIMES | Online – 4 April 2013 – The most rigorous study to date of how much it costs to care for Americans with dementia found that the financial burden is at least as high as that of heart disease or cancer, and is probably higher.[1] Both the costs and the number of people with dementia will more than double within 30 years, skyrocketing at a rate that rarely occurs with chronic disease. The research ... provides the most reliable basis yet for measuring the scale of the problem. Behind the numbers is a sense that the country, facing the aging of the baby boom generation, is unprepared for the coming surge in the cost and cases of dementia. http://www.nytimes.com/2013/04/04/health/dementia-care-costs-are-soaring-study-finds.html?ref=health&_r=0

Specialist Publications

'Palliative care for dementia – time to think again?' (p.14), in *QJM.*

1. 'Monetary costs of dementia in the United States,' *New England Journal of Medicine*, 2013; 368(14):1326-1334. http://www.nejm.org/doi/full/10.1056/NEJMsa1204629

Noted in Media Watch, 25 March 2013:

- NATIONAL PUBLIC RADIO | Online – 19 March 2013 – **'Alzheimer's 'epidemic' now a deadlier threat to elderly.'** Alzheimer's disease is the sixth leading cause of death in the U.S. and figures ... show that deaths from the disease increased by 68% between 2000 and 2010. http://www.npr.org/blogs/health/2013/03/19/174651566/alzheimers-epidemic-now-a-deadlier-threat-to-elderly

Noted in Media Watch, 14 January 2013:

- *END OF LIFE JOURNAL*, 2013;3(1). **'Talking about death in dementia.'** Although dementia may strip away memories and coherent verbal communication, it does not take away feelings, such as shame, embarrassment, pride, happiness, empathy, fear, anxiety, or the sense of... http://endoflifejournal.stchristophers.org.uk/clinical-skills/communication-vignettes-talking-about-death-in-dementia

N.B. Several articles on end-of-life care for people with dementia are noted in this issue of Media Watch (p.9).

Patients teach doctor how to heal at the end of life

CALIFORNIA | *New America Media* – 3 April 2013 – How does a doctor specializing in saving lives turn into one of the nation's leading experts – and medical educators – on end-of-life care? Dr. Vyjeyanthi "V.J." Periyakoil says her 25-year journey from medical school in her native India to directing Stanford University's palliative-care fellowship program taught her that the art of healing lies in listening to her patients. What she heard wasn't always in the medical textbooks. And what they told her led Periyakoil to becoming a leading voice in the movement to re-think end-of-life care from limited hospice treatment in the last six months of life to comprehensive treatment for profoundly ill people – especially those from many cultures, beginning far earlier and actually extending many patients' lives. http://newamericamedia.org/2013/04/patients-teach-doctor-how-to-heal-at-the-end-of-life.php

End of life healthcare trends

OHIO | Center for Health Affairs (Cleveland) – 3 April 2013 – *Healthcare at the End of Life: A Look at Current Trends* ... is intended to provide a starting place for the difficult but important conversation about end-of-life care. There are more options than ever available to ease the discomfort of patients and the sorrow of loved ones for terminally ill individuals. http://www.chanet.org/TheCenterForHealthAffairs/MediaCenter/NewsReleases/~/media/506C5B21D4A74EABAB5600DB2102FFB4.ashx

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CONNECTICUT | NBC News – 5 April 2013 – **'Assisted suicide bill pulled from agenda.'** Lawmakers have removed from the agenda an "assisted suicide bill" that would have allowed doctors to prescribe medication to help a terminally ill patient end his or her life. The bill that was before the Legislature's Public Health Committee, would have affected those with less than six months to live and would allow the medication to be given upon request. State lawmakers had to make their decision before the end of the day today so that the legislation could be sent to the House for further consideration. Supporters said the legislation was pulled to avoid lengthy discussion or filibuster that could jeopardize other vital bills on the day of the committee's deadline to raise bills. http://www.nbcconnecticut.com/news/local/Lawmakers-to-Debate-Assisted-Suicide-Bill--201623681.html
- MINNESOTA | *The Washington Post* – 4 April 2013 – **'Prosecutors appeal ruling in assisted-suicide case against members of Final Exit Network.'** The appeal comes in the case against four members of national right-to-die group Final Exit Network who were charged last year in the 2007 death of Doreen Dunn, an Apple Valley woman who killed herself in her home. Prosecutors argued that defendants not only supported Dunn's decision to kill herself, but provided her with information and support to follow through. Defense attorneys argued that while the state may bar someone from "assisting" a suicide, it is unconstitutional for the state to ban "advising" or "encouraging" a suicide – as stated in the Minnesota statute – because that is pure speech. Prosecutors have argued the statute is narrowly worded so advocates of suicide may freely speak their minds but that those who "intentionally" assist, encourage or advise suicide are breaking the law. http://www.washingtonpost.com/national/health-science/minn-prosecutors-appeal-ruling-in-assisted-suicide-case-against-members-of-final-exit-network/2013/04/04/5dcbb91e-9d73-11e2-9219-51eb8387e8f1_story.html

International

Pediatric palliative care

Palliative care project launched

ZIMBABWE | *The Standard* (Birchenough Bridge)– 7 April 2013 – A local non-governmental organisation, Batsiranai has begun a palliative care programme for abused children in Buhera district. The organisation started a two week long training programme for caregivers at Mudawose rural clinic to kick-start the project. About 30 caregivers drawn from Buhera district were trained. http://www.thestandard.co.zw/2013/04/07/palliative-care-project-launched/

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

'Do not resuscitate' policy amended

U.K. (NORTH IRELAND) | *Londonderry Sentinel* – 6 April 2013 – The Western [Health & Social Care] Trust policy on deciding if patients should be resuscitated or allowed to die after suffering strokes or heart attacks is being amended to ensure doctors only decide on the chances of medical survival and not on patients' potential quality of life. Dr. Matt Cody agreed to amend the Trust's Do Not Attempt Cardiopulmonary Resuscitation policy after a meeting of the Western Trust board. The Consultant Anaesthetist and Chair of the Trust's Resuscitation Committee presented the local health authority's CPR policy to the board in December. The document is designed to give guidance on when and when not to initiate resuscitation in the event of heart attack or stroke. It's designed to ensure good resuscitation planning so that there is timely and effective treatment to make it less likely that critically ill patients will deteriorate to the point of cardiac arrest. According to the latest U.K.-wide data 16.6% of patients survive to discharge after a cardiac arrest. But the Trust's resuscitation policy places the power of life and death in doctors' hands. http://www.londonderrysentinel.co.uk/news/do-not-resuscitate-policy-amended-1-4952824

Eco-friendly burials emerging in China

CHINA RADIO INTERNATIONAL | Online – 5 April 2013 – As the availability of burial plots continues to dwindle and their costs keep increasing, China is encouraging eco-friendly and land-saving burials, but there are challenges to overcome before the efforts will make a difference. Prof. Qiao Kuanyuan from University of Shanghai for Science & Technology says China needs to double its efforts to promote alternative burial options. "Nearly 100,000 people pass away each year in Shanghai. We've managed to keep the area of burial plots for each deceased person to under one square meter, but the total amount is still beyond the capacity of the city. The civil affairs authorities are trying to keep the figure down, but they've not been very successful, because 80 percent of the deceased are still buried underground, with only 20% buried in land-saving services." China promotes a range of eco-friendly, land-saving burials such as tree burials, lawn burials, sea burials and wall burials. http://english.cri.cn/11354/2013/04/05/2361s757768.htm

Noted in Media Watch, 1 April 2013:

- U.K. | *The Economist* – 30 March 2013 –**'Six feet greener.'** Hinton Park [Dorset] is one of over 260 eco-friendly burial sites in Britain. In 1960 only 35% of all funerals involved cremation; now 74% of them do. Less space in churchyards, the rising costs of funerals, and the declining number of Christians have all contributed. http://www.economist.com/news/britain/21574514-funerals-help-environment-are-taking-six-feet-greener

Noted in Media Watch, 20 February 2012

- SOUTH AFRICA | *Daily News* (Cape Town) – 16 February 2012 – **'Past is dead and buried.'** The burden of an increasing global population forces us to reconsider how we deal with our dead. Our present system of burials and cremations is wasteful and unsustainable. http://www.iol.co.za/dailynews/opinion/past-is-dead-and-buried-1.1235620

Noted in Media Watch, 26 April 2010:

- U.S. (CALIFORNIA) | *Wausau Daily Herald* – 23 April 2010 – **'Eco-friendly choices can add meaning to burial.'** For people who want to preserve the environment, the growing practice of green funerals and burials presents a way to make the end of life more meaningful, too. More than half of Americans say they are concerned about the environment; 21% Americans 50+ would prefer an eco-friendly end-of-life ritual. Green represents an ethical and philosophical choice. http://www.wausaudailyherald.com/article/20100423/WDH0101/4230663/1981/WDHsports

Noted in Media Watch, 15 March 2010

'Do green graves change the way we mourn?'

SCIENCE & RELIGION | Online – 12 March 2010 – Choice of how to deal with the body of the deceased is intricately tied to the religious or philosophical perspective of the bereaved. Burial decisions may assist the survivors in finding meaning in their loss. Undoubtedly, the individual who chooses to bury a loved one in a green grave has selected an option that is consistent with his or her worldview and life philosophy. http://www.scienceandreligiontoday.com/2010/03/12/do-green-graves-change-the-way-we-mourn-roxane-cohen-silver-answers/

Corrections & Clarifications

'Learning from PPO Investigations: End-of-life Care,' published by the Prison & Probation Ombudsman (PPO) for England & Wales, was noted in 11 February 2013 edition of Media Watch ('Prison ombudsman: Dying inmates "inappropriately" handcuffed or chained,' *The Guardian*, 5 February 2013). Downloaded the report at http://www.ppo.gov.uk/docs/Learning_from_PPO_investigations_-_End_of_life_care_final_web.pdf

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

Hospital 'death pathway' bribes will be scrapped

U.K. | *The Daily Mail* – 3 April 2013 – Cash bribes to hospitals to put patients on to the controversial Liverpool Care Pathway will be ended. The disclosure means that the National Health Service payments – which amount to at least £30million – are likely to be stopped later this year. A Health Department inquiry is underway into the Pathway, which was originally developed to ease the last days and hours of dying patients. http://www.dailymail.co.uk/news/article-2303136/Hospital-death-pathway-bribes-scrapped-Victory-Mail-ministers-end-payments.html

End-of-life care in Australia

End-of-life care gap 'a disaster'

AUSTRALIA (NEW SOUTH WALES) | *The Newcastle Herald* – 1 April 2013 – Hundreds of patients who die in John Hunter Hospital are being robbed of optimal end-of-life care, putting them at greater risk of a "catastrophic outcome," according to senior staff who describe the situation as a disaster. There are no palliative care staff specialists based at the hospital, leaving junior doctors and nursing staff to rely on support from [neighboring] Calvary Mater Hospital staff. "We are just getting all these reports about sub-optimal management of palliative care issues and of the end-of-life phase at the John Hunter," one senior staff member told the Herald. "To have a hospital the size of John Hunter with no end-of-life care specialists actually full-time on-site is just a disaster." Of the 1500 people who die at the hospital each year, hundreds would benefit from palliative care specialists who could provide better symptom control, pain and prescription management, and respond to acute crises. http://www.theherald.com.au/story/1402431/end-of-life-care-gap-a-disaster/?cs=12

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

The effect of pediatric knowledge on hospice care costs

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 2 April 2013 – The cost of hospice care is rising. Although providing care for children at end of life may be costly for hospices, it is unclear whether or not gaining pediatric knowledge and even establishing a pediatric program may be done cost effective. The purpose of this study was to examine the effect of possessing pediatric knowledge (i.e., pediatric program, pediatric experience) on core hospice care costs. Using 2002 to 2008 California hospice data, the findings of the analysis suggest that having pediatric knowledge does not significantly increase nursing, physician, and medical social service costs. Having a pediatric program was related to increased counseling costs. http://ajh.sagepub.com/content/early/2013/03/26/1049909113484169.abstract

Impact of a palliative care consult service

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 2 April 2013 – Using a retrospective case–control design, the authors analyzed administrative data of patients seen by PCCS [palliative care consult services] while hospitalized at the Rochester, Minnesota Mayo Clinic hospitals from 2003 to 2008. Costs for patients seen and discharged alive were US$35,449 compared to US$37,447 without PCCS consultation. Costs for PCCS patients that died during hospitalization were US$54 940 (95% CI US$51 483-US$58,576) and non-PCCS patients were US$79,660 (95% CI US$76 614-US$83 398). http://ajh.sagepub.com/content/early/2013/03/26/1049909113482746.abstract

Cont.

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 2 April 2013 – **'Professional boundary issues in pediatric palliative care.'** This article explores the hypothesis that when a child has a life-limiting illness, the interpersonal boundaries between the patient, the patient's parents, and the health care team members differ from traditional provider, patient, and parent boundaries because of the unique dynamics of palliative care in pediatrics. http://ajh.sagepub.com/content/early/2013/03/26/1049909113483539.abstract

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 April 2012 – **'Pediatric palliative care in Canada and the U.S.: A qualitative Meta-summary of the needs of patients and families.'** Findings were ... grouped into ... domains pertaining to patient and family needs: interactions with staff, health care delivery and accessibility, information needs, bereavement needs, psychosocial needs, spiritual needs, pain and symptom management, cultural needs, sibling's needs, and decision making. http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0076

Demonstrations of clinical initiatives to improve palliative care in the emergency department: A report from the IPAL-EM initiative

ANNALS OF EMERGENCY MEDICINE | Online – 30 March 2013 – The authors describe clinical demonstrations of emergency department (ED) and palliative care integration to include traditional consultation services with hospital-based palliative care consultants through advanced integration demonstrations in which the ED provides subspecialty palliative care practice. Interviews of 11 program leaders were conducted to describe key elements of the ED-palliative care integration, to include structure, function and process of the programs, as well as strengths, areas of improvement, and any tools or outcome measures developed. In this limited number of programs, a variety of strategies are used to integrate palliative care in the ED, from traditional consultation to well-defined partnerships that include board-certified emergency clinicians in hospice and palliative medicine. http://www.sciencedirect.com/science/article/pii/S0196064413000425

Noted in Media Watch, 14 November 2011:

- CENTER TO ADVANCE PALLIATIVE CARE | Press release – 10 October 2011 – **'IPAL-EM launches to improve palliative care in emergency medicine.'** A new national initiative will integrate and increase the use of palliative care when seriously ill patients are admitted to the emergency department. http://www.eurekalert.org/pub_releases/2011-11/tmsh-ilt110411.php

Employment status and work-related difficulties among family members of terminally ill patients compared with the general population

ASIAN PACIFIC JOURNAL OF CANCER PREVENTION, 2013;14(1):373-379. Although caregiving to patients with terminal illness is known to be a stressful burden to family members, little attention has been focused on work-related problems. Compared with the general population, the percentage of [study participants] not working among the family caregivers was higher. A major reason for not working was to provide assistance to the patients; 40.6% of those who continued working and 32.3% of those not working family members reported extreme fatigue. Caregivers of old age, those who were female, those with a lower household income, and those caring for patients with a low performance status were not working at a more significant rate. http://www.apocpcontrol.org/page/apjcp_issues_view.php?pno=4113&gubun=p&s_search=&s_paper_vol=&s_number33=

Noted in Media Watch, 30 January 2012:

- *INTERNATIONAL JOURNAL OF WORKPLACE HEALTH MANAGEMENT*, 2012;5(1). **'Family friendly policies: Accommodating end-of-life caregivers in workplaces.'** The findings of this study can directly inform workplace practice, both now and in the years to come, regarding how best to support workers who are also providing informal end-of-life care to family, friends, and others. http://www.emeraldinsight.com/journals.htm?articleid=17014292&show=abstract

Part 4 of a four-part series

Online resources for culturally and linguistically appropriate services in home healthcare and hospice: Resources for European patients

HOME HEALTHCARE NURSE, 2013;31(3):158-166. Provision of culturally and linguistically appropriate care for home care and hospice patients is a national mandate. Finding patient-education materials in languages other than English can be a challenge for clinicians in workplaces lacking affiliation with a hospital that provides multilingual resources to its patients. Many hospitals, government agencies, and foundations have made appropriate resources freely available on the Internet. However, identifying them is time consuming. This article reviews a variety of sources for access to patient-education materials in the multiple languages of Europe. http://journals.lww.com/homehealthcarenurseonline/Fulltext/2013/03000/Online_Resources_for_Culturally_and_Linguistically.8.aspx

1. Part 3: Resources for Middle Eastern patients, *Home Healthcare Nurse*, 2013;31(1):26-28. http://journals.lww.com/homehealthcarenurseonline/Fulltext/2013/01000/Resources_for_Middle_Eastern_Patients__Online.5.aspx
2. Part 2: Resources for Asian patients, *Home Healthcare Nurse*, 2012;30(4):225-232. http://journals.lww.com/homehealthcarenurseonline/Fulltext/2012/04000/Online_Resources_for_Culturally_and_Linguistically.4.aspx
3. Part 1: Resources for Spanish-speaking patients, *Home Healthcare Nurse*, 2012;30(1):E1-E7. http://journals.lww.com/homehealthcarenurseonline/Abstract/2012/01000/Online_Resources_for_Culturally_and_Linguistically.17.aspx

End-of-life care in The Netherlands

Palliative care case management in primary care settings: A nationwide survey

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online – 1 April 2013 – The authors identified 20 initiatives for case management. All stated that case management is supplemental to other care. In all initiatives the case managers are registered nurses and most possess higher vocational education and/or further training. All initiatives seek to identify the multidimensional care needs of the patients and the relatives and friends who care for them. Almost all provide information and support and refer patients who need care. Differences are found between the organisations offering the case management, their target groups, the names of the initiatives and whether direct patient care is provided by the case manager. Research is needed to gain insight into the best way to deliver case management. By describing characteristics of case management in palliative care, an important first step is made in identifying effective elements of case management. http://www.journalofnursingstudies.com/article/S0020-7489(13)00070-9/abstract

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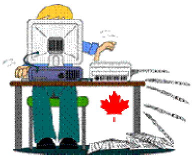

Barry R. Ashpole

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

From the archives:

- *BMC HEALTH SERVICES RESEARCH* | Online – 18 June 2012 – **'What is case management in palliative care? An expert panel study.'** Case management in palliative care shows a high level of variability in implementation choices. It should aim at maintaining continuity of care to ensure that patients and those close to them experience care as personalised, coherent and consistent. http://www.biomedcentral.com/content/pdf/1472-6963-12-163.pdf

- *JOURNAL OF PALLIATIVE CARE*, 2004;7(1):119-134. **'Integrating case management and palliative care.'** Most seriously ill Americans live at home under the care of their primary physician and with the support of family caregivers. To reduce costs while simultaneously improving the quality of patient care, insurers have increasingly turned to the concept of case management. http://online.liebertpub.com/doi/abs/10.1089/109662104322737395

Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics

INTERNATIONAL JOURNAL OF PUBLIC HEALTH, 2013;58(2):257-267. Over 16 million deaths are reported in 45 populations. Half reported 54% or more of all deaths occurred in hospitals, ranging from Japan (78%) to China (20%). Of 21 populations reporting deaths of older people, a median of 18% died in residential aged care, with percentages doubling with each 10-year increase in age, and 40% higher among women. This place of death study includes more populations than any other known. In many populations, residential aged care was an important site of death for older people, indicating the need to optimise models of end-of-life care in this setting. For many countries, more standardised reporting of place of death would inform policies and planning of services to support end-of-life care. http://link.springer.com/article/10.1007/s00038-012-0394-5

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2013;3(1):128-129. **'Changes in place of death preferences in patients receiving specialist palliative care: A retrospective case note review.'** Preference for place of death changes. Most patients [i.e., study participants] chose a place they are familiar with. Patients who experienced hospice admission were more likely to choose this option. http://spcare.bmj.com/content/3/1/128.3.short

Noted in Media Watch, 25 February 2013:

- *EUROPEAN JOURNAL OF CANCER* | Online – 18 February 2013 – **'Awareness of general practitioners concerning cancer patients' preferences for place of death: Evidence from four European countries.'** Despite the importance of being able to die in a preferred location, GPs [i.e., study participants] were often unaware about patient preferences, especially in Italy and Spain. If GPs were informed, the preference was often met in all countries, indicating room for improvement in end-of-life care. http://www.ejcancer.info/article/S0959-8049(13)00044-0/abstract

From the archives:

- *PALLIATIVE MEDICINE*, 2008;22(7):787-795. **'Preference for place of care and place of death in palliative care: Are these different questions?'** This study suggests there are two conversations: preference for current place of care and preference for care at the time of death.http://pmj.sagepub.com/content/22/7/787.abstract?ijkey=399a2c1a68addd1988feb31d6ee8d6a27ef37ca4&keytype2=tf_ipsecsha

Family presence during cardiopulmonary resuscitation: Who should decide?

JOURNAL OF MEDICAL ETHICS | Online – 4 April 2013 – Even though a great deal of evidence and professional guidelines support the option of family presence during resuscitation (FPDR), many healthcare professionals still oppose it. One of the main arguments espoused by the latter is that family members should not be allowed for the sake of the patient's best interests, whether it is to increase his chances of survival, respect his privacy or leave his family with a last positive impression of him. The authors examine the issue of FPDR from the patient's point of view. Since the patient requires CPR, he is invariably unconscious and therefore incompetent. They discuss the autonomy principle and the three-tiered process for surrogate decision making, as well as the beneficence principle and show that these are limited in providing us with an adequate tool for decision making in this particular case. http://jme.bmj.com/content/early/2013/04/03/medethics-2012-100715.abstract

Noted in Media Watch, 18 March 2013:

- U.S. | *The New York Times* – 14 March 2013 – **'Families may gain from observing CPR.'** It seems counterintuitive: allowing family members of deathly ill patients to watch while doctors try to restart the patients' hearts. But a new study ... has found that family members who observed resuscitation efforts were significantly less likely to experience symptoms of post-traumatic stress, anxiety and depression than family members who did not.[1] http://www.nytimes.com/2013/03/14/health/viewing-cpr-benefits-patients-families-study-finds.html?ref=health&_r=0

    1. 'Family presence during cardiopulmonary resuscitation,' *New England Journal of Medicine*, 14 March 2013. Family presence during CPR was associated with positive results on psychological variables and did not interfere with medical efforts, increase stress in the health care... http://www.nejm.org/doi/full/10.1056/NEJMoa1203366?query=featured_home

Palliative care and end-of-life planning in Parkinson's disease

JOURNAL OF NEURAL TRANSMISSION, 2013;120(4):635-638. Decisions about interventions towards the end of life, such as insertion of percutaneous endoscopic gastrostomy (PEG) tube for nutrition, can be very challenging, particularly if, as in most cases, the person with PD [Parkinson's disease] has not previously expressed their views upon this while they still maintained capacity to make decisions. Advance care planning (ACP) in PD should be encouraged in relation to interventions such as PEG tubes. It may also cover issues such as preferred place of death. Over recent years lower proportions of people have been dying at home, and this is especially true for PD, but home may well be where they would have preferred to die. However, there is little evidence to guide health professionals about how, when, and by whom, ACP should be approached. http://link.springer.com/article/10.1007/s00702-013-0967-3

Of related interest:

- *JOURNAL OF HEART & LUNG TRANSPLANTATION*, 2013;32(4):S160-S161. **'End stage heart failure: Cardiologists' reluctance to discuss end of life care.'** Despite practitioners' belief patients with end stage HF [heart failure] have severe symptoms and cardiologists should initiate EOL [end-of-life] care discussions almost half of respondents were unsure when to refer to hospice and whether it would be accepted. http://www.jhltonline.org/article/S1053-2498(13)00387-2/abstract

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 2 April 2013 – **'Oncologists' strategies and barriers to effective communication about the end of life.'** Strategies to effective communication about the end of life include: being open and honest; having ongoing, early conversations; communicating about modifying treatment goals; and balancing hope and reality. http://jop.ascopubs.org/content/early/2013/04/02/JOP.2012.000800.abstract

Translating spiritual care in the chaplain profession

JOURNAL OF PASTORAL CARE & COUNSELING, 2013;67(1). Despite evidence documenting improvements quality of life for patients using spiritual services, chaplains experience challenges in translating the benefits they provide into concepts understood by patients, team members, and administrators. A qualitative study using interviews with 19 chaplains found that translation problems occur in three main areas: a) justifying the role to patients and families; b) determinations of what constitutes a "productive" employee; and, c) effective collaboration with other members of the health care team. This study outlines strategies to ease the process of translation, as well as some directions for future research. http://journals.sfu.ca/jpcp/index.php/jpcp/article/view/600

Noted in Media Watch, 9 July 2012:

- *BMC PALLIATIVE CARE* | Online – 2 July 2012 – **'A national study of chaplaincy services and end-of-life outcomes.'** Study findings suggest chaplaincy services may play a role in increasing hospice enrollment ... attributable to chaplains' assistance to patients and families in making decisions about care at the end-of-life, perhaps by aligning their values and wishes with actual treatment plans. http://www.biomedcentral.com/content/pdf/1472-684X-11-10.pdf

Cont. next page

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Media Watch Online

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/ (Scroll down to 'Palliative Care Network: Media Watch')

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: http://palliativecarewa.asn.au/site/helpful-resources/ (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://www.hpcconnection.ca/newsletter/inthenews.html

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

ONTARIO | Palliative Care Consultation Program (Oakville): http://www.palliativecareconsultation.ca/?q=mediawatch

Europe

HUNGARY | Hungarian Hospice Foundation: http://www.hospicehaz.hu/en/training/ (Scroll down to 'Media Watch')

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

International

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)

Noted in Media Watch, 24 January 2011:

- *PALLIATIVE MEDICINE*, 2011;25(1):21-25. **'Hope beyond (redundant) hope: How chaplains work with dying patients.'** The author identifies four organic moments in the chaplain-patient relationship, each moment being a discernible development in the chaplain's being-with the patient: "evocative presence," "accompanying presence," "comforting presence," and "hopeful presence." http://pmj.sagepub.com/content/25/1/21.abstract

Neuropsychological correlates of complicated grief in older spousally bereaved adults

JOURNALS OF GERONTOLOGY | Online – 3 April 2013 – This study furthers our understanding of the characteristics that distinguish complicated grief. The authors expand on previous research by a) testing older adults; b) excluding those with co-morbid major depressive disorder; c) using participant-chosen grief-related stimuli; and, d) using a married, non-bereaved control group. Results indicate longer reaction time across 3 blocks of grief-related words in the complicated grief group but no difference across 3 blocks of the neutral words. The 3 groups performed comparably on the other neuro-cognitive tasks, indicating no cognitive differences in working memory or set shifting between groups. Furthermore, these effects of complicated grief generalize to older adults and appear independent of major depression. Complicated grief has cognitive interference as a neuropsychological component highlighting it as distinct from non-complicated grief. http://psychsocgerontology.oxfordjournals.org/content/early/2013/04/03/geronb.gbt025.short

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 April 2013 – **'The impact of dreams of the deceased on bereavement: A survey of hospice caregivers.'** The results of this study support the theory that dreams of the deceased are highly prevalent among – and often deeply meaningful for – the bereaved. While many counselors are uncomfortable working with dreams in psychotherapy, the present study demonstrates their therapeutic relevance to the bereaved population and emphasizes the importance for grief counselors to increase their awareness, knowledge, and skills with regards to working with dreams. http://ajh.sagepub.com/content/early/2013/03/26/1049909113479201.abstract

The role of palliative care in patients with neurological diseases

NATURE REVIEWS: NEUROLOGY | Online – 2 April 2013 – Palliative care ... applies to a large and growing proportion of neurological disorders, most prominently stroke and dementia. Challenges in the palliative care of patients with incurable neurological diseases include the broad spectrum of the rate of symptom progression, a lack of reliable prognostic markers, scarcity of evidence for efficacy of symptomatic treatments, and a high prevalence of difficulties with communication, cognitive impairment and behavioural disturbances. A genuinely multidisciplinary approach to neurological palliative care is, therefore, required. However, palliative care is not an integral part of neurological training in most countries. This Perspectives article aims to underscore the importance of integrating palliative care into daily clinical practice. The basic principles and challenges of neurological palliative care are also outlined in the light of relevant literature. http://www.nature.com/nrneurol/journal/vaop/ncurrent/full/nrneurol.2013.49.html

Noted in Media Watch, 15 November, 2010:

- U.K. | National End of Life Care Programme – 11 November 2010 – **'End of life care in long term neurological conditions.'** *A framework for implementation* ... suggests that there is often little discussion about end of life provision for people with long term neurological conditions.[1] http://www.mstrust.org.uk/news/article.jsp?id=4323

    1. *End of life care in long term neurological conditions*, National End of Life Care Programme, November 2010. http://www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-in-long-term-neurological-conditions-a-framework

Palliative care services: A comparison between Romania and Hungary

PALIAŢIA, 2013;6(2). The first palliative care service was established in Romania in 1992, and in Hungary in 1991. Absence of approved minimum standards in Romania is an unfavourable aspect for the establishment and development of qualitative palliative care services. Positive developments in Romania are that these services are funded by The National Insurance House, that palliative care services have developed rapidly in the last twenty years, that there is a large number of specialists trained in this field, and that the National Association of Palliative Care is now recognised internationally. After analyzing data on the number of palliative care services, legislation, population and patients with incurable diseases in terminal stage of the two countries, we conclude that there is a inadequate development of palliative care services in Romania, compared to Hungary. http://www.paliatia.eu/new/2013/04/palliative-care-services-a-comparison-between-romania-and-hungary/

Noted in Media Watch, 20 February 2013:

- *PALIAŢIA* (Romania) | Online – 16 February 2012 – **'Palliative care in Central and Eastern Europe.'** Despite economic crisis and poverty, palliative care is steadily spreading in the Central and Eastern Europe. http://www.paliatia.eu/modules/smartsection/item.php?itemid=300

Palliative care for dementia – time to think again?

QJM | Online – 4 April 2013 – It is estimated that there are 35.6 million people with dementia worldwide and this is projected to increase to over 115 million by the year 2050. End-of-life care received by this group is often poor and does not equate to that offered in other life limiting illnesses. This review highlights results from a large U.K. study of informal carers of people with dementia to explore what are determinants of care for people with dementia and their family carers. http://qjmed.oxfordjournals.org/content/early/2013/04/02/qjmed.hct078.abstract

Media Watch: Editorial Practice

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

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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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.

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *THE AUSTRALIAN HUMANIST*, 2013;109:11-14. **'The case for euthanasia and physician-assisted suicide.'** As the law currently stands, there is a complete ban on both euthanasia and assistance in suicide. Even following a request by a patient, a medical practitioner who directly takes the life of his or her patient, can be charged with murder or manslaughter. Despite the repeal of laws that forbade committing or attempting to commit suicide, laws still exist which proscribe the provision of assistance to another to commit or attempt to commit suicide. http://search.informit.com.au/documentSummary;dn=214952512449471;res=IELHSS

Worth Repeating

Reflection

Precarious hope

AMERICAN JOURNAL OF NURSING, 2012; 112(12):72. In hospice, I'm often confronted with the difficulty of balancing honesty with kindness. I love a quote often attributed to the Buddha: "When words are both true and kind, they can change our world." It follows that sometimes what is *true* is *not* kind, and that *truth must* be cloaked in kindness – as in this instance, as I sit at the table listening to George, whose hopeful, unrealistic comments confirm that he simply *can't* hear the truth. The notes in his chart inform me there have been other discussions – with the palliative care team during his last hospitalization, as well as conferences between his physicians, his adult children, and the discharge planners. He desperately wants things to remain unchanged, even with his steadily waning energy, as the cancer steals his life away. He needs to hold on to his dream. The truth is this: *he won't be able to stay here and continue caring for his wife; soon he may be bedridden*. There will be a collapse in this fragile care-giving system. My dilemma is I understand his futile hope and I find myself not wanting to be the dream-breaker. We talk about his hopes: he'd like to stay in his home and have death occur naturally. I hope this for him, too; I just worry it probably won't happen. He will end up in the hospital, because neither he nor his family has a plan B, and he'll likely end his days in a nursing home. I'm sick that we have so few options for people without either the family willing or able to step in to be caretakers or enough money to provide around-the-clock caregiving in the home. http://journals.lww.com/ajnonline/Fulltext/2012/12000/Precarious_Hope.37.aspx

Extract from journal *American Journal of Nursing* article

In our local hospice slang, they are known as a "tepee couple." Visualize a carefully constructed, strong, but potentially vulnerable affair; if one of the poles is removed, the whole thing becomes unstable and is easily dismantled.
