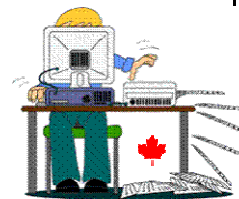


Media Watch...

*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.*

15 September 2014 Edition | Issue #375



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Compiled & Annotated by Barry R. Ashpole

A gatekeeper to hospital services: Scroll down to [Specialist Publications](#) and 'The family physician's perceived role in preventing and guiding hospital admissions at the end of life: A focus group study' (p.8), in *Annals of Family Medicine*.

Canada

Group urges equal access palliative care strategy for New Brunswick

NEW BRUNSWICK | Globe TV News (Moncton) – 12 September 2014 – A group that cares for terminally ill patients in New Brunswick says the province isn't providing equal access to end-of-life care. The New Brunswick Hospice Palliative Care Association wants New Brunswick to adopt a provincial strategy for hospice palliative care that includes better training and pay for personal support workers, sustainable funding for residential hospices and equal access to this care across the province. Currently, access to palliative care depends on where you live. In Saint John, there is a 10-bed residential hospice, but in Campbellton, there are only 16 palliative physician hours allotted per week, according to Dr. Pam Mansfield, clinical director of palliative care at the Moncton Hospital. She said part of the problem is the funding strategy for the operating costs at the hospice in Saint John. The government provides 45% of the funds, while the community must fundraise the remaining 55% each year, which holds back other communities from establishing their own residential hospices. <http://globalnews.ca/news/1558829/group-urges-equal-access-palliative-care-strategy-for-new-brunswick/>

Noted in Media Watch, 11 August 2014, #370 (p.2):

- NEW BRUNSWICK | CBC News (Dalhousie) – 6 August 2014 – **'Dalhousie residents demand to keep palliative care beds.'** Dalhousie-area residents are upset about the loss of four palliative care beds at the St. Joseph Community Health Centre in the northern town. <http://www.cbc.ca/news/canada/new-brunswick/dalhousie-residents-demand-to-keep-palliative-care-beds-1.2729087>

Noted in Media Watch, 27 September 2010, #168 (p.1):

- NEW BRUNSWICK | CBC News (Saint John) – 22 September 2010 – **'Hospices needed province-wide: Doctor.'** New Brunswick's first residential hospice is set to open in Saint John, but health-care professionals ... say the need for such facilities is critical across the province. <http://www.cbc.ca/canada/new-brunswick/story/2010/09/22/nb-hospice-need-moncton.html>

Home care needs of many Canadians go unmet: Statistics Canada

CTV NEWS | Online – 9 September 2014 – A study by Statistics Canada has found the needs of many Canadians who require home care for long-term illnesses, aging or disabilities aren't being fully met.¹ A 2012 survey found 792,000 Canadians aged 15 years and older who require home care reported their needs were only partly met or not met at all. That compares to 1.8 million care recipients who said they got all the care they needed. The agency's survey did not count people living in institutions or long-term care facilities. Of the Canadians whose needs weren't being met, about 461,000 said they did not receive any care. Another 331,000 people said they were getting some care but not all that they needed. <http://www.ctvnews.ca/health/home-care-needs-of-many-canadians-go-unmet-statistics-canada-1.1998250>

1. 'Study: Canadians with unmet home care needs, 2012,' Statistics Canada, September 2014. <http://www.statcan.gc.ca/daily-quotidien/140909/dq140909a-eng.htm?HPA>

Of related interest:

- NOVA SCOTIA | CBC News – 8 September 2014 – '**First Nations elder care in the hands of family members.**' First Nations communities in Nova Scotia are working hard to keep their aging family members out of nursing homes and connected to their culture. According to the Department of Health & Wellness, as of 22 August 2014 there were 7,821 people in long term care, including people in assisted living residential care facilities and nursing homes – 60 of those are of aboriginal descent. <http://www.cbc.ca/news/canada/nova-scotia/first-nations-elder-care-in-the-hands-of-family-members-1.2758934>

N.B. *Canada's Most Vulnerable: Improving Health Care for First Nations, Metis & Inuit Seniors*, The Health Council of Canada, November 2013. [Noted in Media Watch, 2 December 2013, #334 (p.1)] http://healthcouncilcanada.ca/rpt_det_gen.php?id=801&rf=2

- BRITISH COLUMBIA | *The Vancouver Sun* – 6 September 2014 – '**Seniors' health in the spotlight: High staff turnover plagues home care sector.**' Government and individuals spent between \$7-8 billion in 2010 on publicly funded and private home care, reports the Conference Board of Canada, making up about four per cent of all health care spending across the country.¹ That marks an astonishing increase from an estimated \$4.3 billion in combined spending in 2003-2004, according to a report by the Canadian Institute for Health Information.² <http://www.vancouversun.com/health/Seniors+health+spotlight+High+staff+turnover+plagues+home+care+sector/10179447/story.html>

1. 'Home and Community Care in Canada: An Economic Footprint,' Conference Board of Canada, May 2012. <http://www.conferenceboard.ca/e-library/abstract.aspx?did=4841>
2. 'Home Care,' Canadian Institute for Health Information, Accessed 8 September 2014. The Institute collects and reports on clinical, administrative and resource utilization data from publicly funded home care programs in Canada. <http://www.cihi.ca/cihi-ext-portal/internet/en/tabbedcontent/types-of+care/community+care/home+care/cihi021338>

Critically ill hospital patients underfed, making them more likely to die: Study

THE NATIONAL POST – 7 September 2014 – A majority of the critically ill patients in hospitals worldwide – including the most fragile amongst them – receive too little nutrition, making them more likely to die or suffer a drawn-out recovery, suggests a new Canadian study.¹ The "under-feeding" problem likely stems from a medical mindset that sees drugs and technology as the chief means to treat the very sick, and fails to recognize that food can be therapy, too, says Daren Heyland, the critical care doctor who spearheaded the research. "Nutrition as a general rule is under-valued by the medical profession," said Dr. Heyland, a professor at Queen's University... <http://news.nationalpost.com/2014/09/07/critically-ill-hospital-patients-underfed-making-them-more-likely-to-die-study/>

1. 'The prevalence of iatrogenic underfeeding in the nutritionally "at-risk" critically ill patient: Results of an international, multicenter, prospective study,' *Clinical Nutrition*, 18 July 2014. [http://www.clinicalnutritionjournal.com/article/S0261-5614\(14\)00184-8/abstract](http://www.clinicalnutritionjournal.com/article/S0261-5614(14)00184-8/abstract)

U.S.A.

Can we have a fact-based conversation about end-of-life planning?

THE NEW YORK TIMES | Online – 10 September 2014 – Dealing with health care needs at the end of life is a difficult but unavoidable issue in an aging society with rising health care costs like ours. After a failed attempt to deal with the issue as part of the Affordable Care Act, it may again be returning to the policy agenda. Can we avoid another catastrophic bout of misinformation? The debate over end-of-life planning has largely been dormant since 2009, when the former Alaska governor Sarah Palin's false claim that President Obama's health care plan included a "death panel" spelled the end of a proposal for Medicare to reimburse doctors for voluntary end-of-life consultations with patients. The Obama administration briefly issued and then withdrew a regulation that would have added end-of-life consultation coverage to Medicare in early 2011, but is likely to revisit the issue after receiving a recommendation from an influential American Medical Association panel. http://www.nytimes.com/2014/09/11/upshot/can-we-have-a-fact-based-conversation-about-end-of-life-planning.html?_r=0&abt=0002&abg=1

End-of-life discussions should be a given

ANNALS OF LONG-TERM CARE | Online – Accessed 10 September 2014 – Here we are in 2014, and very slowly and incrementally the American public and physicians in general and bureaucrats in the public and private sector are beginning to accept the medical benefits as well as the humanity and respect for individual dignity and autonomy in patient decision-making by supporting (and that usually means funding) discussions by physicians with their patients and often families about end-of-life wishes. In most jurisdictions where the negative stigma of end-of-life planning and what is often in the professional circles is called advance care planning exists and is supported, there is ample evidence that it serves patients and their families, as well as physicians and allied health care professionals. <http://www.annalsoflongtermcare.com/blog/end-of-life-discussions-should-be-given>

Noted in Media Watch, 1 September 2014, #373 (p.2):

- *THE NEW YORK TIMES* | Online – 30 August 2014 – '**Coverage for end-of-life talks gaining ground.**' Medicare may begin covering end-of-life discussions next year if it approves a recent request from the American Medical Association, the country's largest association of physicians and medical students. <http://www.nytimes.com/2014/08/31/health/end-of-life-talks-may-finally-overcome-politics.html>

What cancer patients want and what Medicare covers may differ

REUTERS | Online – 10 September 2014 – When asked what Medicare should cover for cancer patients in their last months of life, many patients and their caregivers choose benefits the federal insurance does not offer, like home-based long term care and concurrent palliative care, according to a new study based on interviews.¹ Given an array of options, a limited budget and a chance to discuss the choices, patients and caregivers were not very likely to devote all coverage to curative cancer treatment, said lead author Donald H. Taylor Jr., of the Sanford School of Public Policy at Duke University in Durham, North Carolina. Medicare covers what it defines as "reasonable and necessary care" and its standards have come to guide what private insurers are willing to pay for as well... As Medicare spending is targeted by federal cost cutting, the risk that patient choices will be narrowed increases... <http://uk.reuters.com/article/2014/09/10/us-medicare-cancer-coverage-preferences-idUKKBN0H524C20140910>

1. 'There is a mismatch between the Medicare benefit package and the preferences of patients with cancer and their caregivers,' *Journal of Clinical Oncology*, 25 August 2014. <http://jco.ascopubs.org/content/early/2014/08/25/JCO.2013.54.2605.abstract>

Near death, and overmedicated

THE NEW YORK TIMES | Online – 9 September 2014 – How sick and disabled, how far into advanced dementia, how close to death do elderly nursing home patients have to be before their physicians stop prescribing drugs that can cause uncomfortable side effects but show scant evidence of helping them? Let me quickly acknowledge that this was my own reaction to a study published on Monday....¹ Researchers use far more measured terms; sometimes the things they report make you wonder how they manage that. Consider this nationwide sample of 5,406 people with a diagnosis of advanced dementia who spent at least 90 days in a nursing home between 2009 and 2010. Most were over age 85 and had other diseases as well. The great majority ... had a do-not-resuscitate order. It's always a heartbreaking situation. Dementia is a terminal disease, although family members don't always recognize that and health care professionals don't always explain it. By definition, these patients can no longer recognize family members; most are bedridden, with a vocabulary that has shrunk to five words or fewer. "They can't walk or feed themselves or communicate meaningfully," said Dr. Jennifer Tjia, a geriatrician and palliative care specialist at the University of Massachusetts Medical School and the study's lead author. "A lot also have severe swallowing difficulties." Moreover, Dr. Tjia added: "These folks have a very high mortality rate. Many die within six months." A number of previous studies have shown that health care proxies, who make medical decisions for such patients, overwhelmingly say that their primary goal is comfort. Yet pharmacy records revealed that most of these patients, almost 54%, received at least one of what the researchers delicately called "medications of questionable benefit." http://newoldage.blogs.nytimes.com/2014/09/09/near-death-and-overmedicated/?_php=true&_type=blogs&ref=health&r=0

1. 'Use of medications of questionable benefit in advanced dementia, *JAMA Internal Medicine*, 8 September 2014. <http://archinte.jamanetwork.com/article.aspx?articleid=1901117>

National Palliative Care Registry Annual Survey Summary: Results of the 2012 National Palliative Care Registry Survey, as of July 2014

CENTER TO ADVANCE PALLIATIVE CARE | Online – 2 September 2014 – Palliative care [PC] in U.S. hospitals continues to increase, according to a new analysis released by the Center. The prevalence of hospitals (50 or more beds) with a PC team increased from 658 (24.5%) to 1,734 (61%) – a 163.5% increase from 2000-2012. In 2000, less than one-quarter of these hospitals (658) had a PC program, compared with more than two-thirds (1,734) in 2012. [https://registry.capc.org/cms/portals/1/Reports/National Palliative Care%20Registry Annual Survey Summary 9.2.2014.pdf](https://registry.capc.org/cms/portals/1/Reports/National_Palliative_Care%20Registry_Annual_Survey_Summary_9.2.2014.pdf)

Specialist Publications

'Reconceptualizing continuing professional development to close long-standing quality gaps in palliative care' (p.7), in *American Journal of Medical Quality*.

'Variation in decisions to forgo life-sustaining therapies in U.S. ICUs: Decisions to forgo life-sustaining therapies' (p.10), in *Chest*.

'American Indians' experiences of life-threatening illness and end of life' (p.13), in *Journal of Hospice & Palliative Nursing*.

Updated 15 September 2014

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.14.

International

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

Many boards "ignore needs of dying"

U.K. (England) | Press Association – 12 September 2014 – The needs of dying people and their families are being "ignored" by many local health bodies, charities warned.¹ Just over four in 10 Health & Wellbeing Boards in England consider the needs of people nearing the end of their lives, according to Help the Hospices and the National Council for Palliative Care. The bodies reviewed strategy documents of the 152 Health & Wellbeing Boards in England to assess whether they considered the needs of people approaching the end of life. They found that twenty-four percent did not make any reference at all to people approaching the end of life or their care needs in their strategies. And 26% only made an "indirect reference" to the needs of dying people, they said. Seven per cent of boards had not published their strategies or had not made them publicly available. The organisations expressed concerns about their findings, saying that at present around 92,000 people die each year without the support they need.
<http://www.ncpc.org.uk/news/hwb-report>

1. 'Mapping England's Health & Wellbeing Boards' vision of dying people,' Help the Hospices and the National Council for Palliative Care, September 2014.
http://www.ncpc.org.uk/sites/default/files/HWBs_Report.pdf

Noted in Media Watch, 25 March 2014, #298 (p.6):

- U.K. (England) | National Council for Palliative Care – 21 March 2013 – **'Time running out for Health & Wellbeing Boards to consider needs of dying people.'** With two weeks to go until England's 152 Health & Wellbeing Boards take on legal responsibilities as part of the Government's health reforms, almost half have failed to set out what they will do to meet the needs of dying people. 'Does dying matter to England's new Health & Wellbeing Boards?' finds of Boards who have made public their strategy only just over half (63 out of 117) had explicitly discussed end of life care despite the fact on average almost 3,000 people each year will die...
<http://www.ncpc.org.uk/sites/default/files/NCPC%20Mapping%20EOLC%20Health%20and%20Wellbeing%20strategy%20briefing%20Feb2013.pdf>

Healthcare funds distribution unfair, audit finds

U.K. (England) | *The Guardian* – 11 September 2014 – Some local healthcare services in England have been underfunded because of an unfair Whitehall system to allocate £79 billion in resources, a report by the government's auditors has concluded.¹ The government is making slow progress towards a proper and accurate distribution of money to local commissioners of healthcare, the National Audit Office said. Many decisions are being made on individual civil servants' judgments instead of being based on evidence...
<http://www.theguardian.com/society/2014/sep/11/healthcare-funds-distribution-unfair-audit-finds>

1. 'Funding healthcare: Making allocations to local areas,' National Audit Office, September 2014.
<http://www.nao.org.uk/wp-content/uploads/2014/09/Funding-healthcare-making-allocations-to-local-areas.pdf>

N.B. There is no mention in the National Audit Office report of end-of-life care, hospice or palliative care.

Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>



End-of-life care funding in New Zealand

Palliative care rise strains funding

NEW ZEALAND | *The Southland Times* – 8 September 2014 – Southern hospices are fighting million-dollar funding shortfalls to provide care for patients, as the demand for palliative services increases. Hospice Southland raised \$1.8 million in the past financial year to cover the shortfall left by government funding and is facing a similar deficit this year. Chief executive Andrew Leys said government funding covered about 50% of the hospice's operating costs. The hospice received \$1,747,013 of government funding in the past financial year, but worked with a net operating deficit of \$1,781,402. This had to be made up by donations, grants, shop sales and bequests through the year, he said. The biggest cost – about 80% – was staff wages. The majority of wage costs were to pay for clinical support staff, Leys said. The variable nature of bequests and donations made it difficult to budget operational costs, he said. The hospice service is provided free for palliative care patients... <http://www.stuff.co.nz/southland-times/news/10470295/Palliative-care-rise-strains-funding>

Noted in Media Watch, 1 September 2014, #373 (p.6):

- NEW ZEALAND | *Bay of Plenty Times* (Tauranga) – 26 August 2014 – **'Patient numbers overtake hospice funding.'** The number of patients under Waipuna's Hospice care has increased by more than 100% over the past four years and funding has not kept up with the rapid increase. In 2010, the hospice had 140 patients on its books "at any one time" compared to 292 now. Its funding model with the Bay of Plenty District Health Board had also dropped from 70% received in 2009 to 56% funding. http://www.nzherald.co.nz/bay-of-plenty-times/news/article.cfm?c_id=1503343&objectid=11314293

Noted in Media Watch, 30 September 2013, #325 (p.5):

- NEW ZEALAND | *The Waikato Times* – 27 September 2013 – **'Hospice hit hard by "double-whammy."** In its 2012-2013 report Hospice Waikato revealed while referrals to its services had gone up by 28%, income from grants had gone down by \$177,000 over the same period. <http://www.stuff.co.nz/waikato-times/news/9215575/Hospice-hit-hard-by-double-whammy>

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

Integrating early palliative care for patients with HIV: Provider and patient perceptions of symptoms and need for services

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 12 September 2014 – Within an inner-city medical center, the authors began a program to integrate early palliative care into HIV inpatient care. Providers ranked their patients' fatigue, sadness, anxiety, sexual dysfunction, and body image significantly higher than patients did for themselves. Patients ranked medical care, pharmacy, social work, physical therapy, and housing as significantly more important to them than providers estimated them to be. These differences may reflect the fact that physicians often overlook patients' unmet basic needs. Early palliative care may narrow this gap between providers' and patients' perceptions of needs through good communication and targeting barriers, such as housing instability, which are vital to overcome for consistent long-term follow up. <http://ajh.sagepub.com/content/early/2014/09/11/1049909114550391.abstract>

Of related interest:

- AIDS CARE | Online – 8 September 2014 – **'Preferences for professional versus informal care at end of life amongst African-American drug users with HIV/AIDS.'** Findings suggest interventions to promote informal end-of-life care should bolster supportive resources and skills for care provision and treatment adherence support, and address perceived norms of reciprocity. <http://www.tandfonline.com/doi/abs/10.1080/09540121.2014.951307#.VBQx-ZRdXYQ>

Palliative care issues in amyotrophic lateral sclerosis: An evidenced-based review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 September 2014 – As palliative care physicians become increasingly involved in the care of patients with ALS, they will be asked to provide guidance regarding the use of supplements, diet, exercise, and other common preventive medicine interventions. Moreover, palliative care physicians have a crucial role assisting patients with ALS in addressing health care decisions to maximize quality of life and cope with a rapidly disabling disease. It is therefore important for palliative care physicians to be familiar with commonly encountered palliative care issues in ALS. This article provides an evidenced-based review of palliative care options not usually addressed in national and international ALS guidelines. <http://ajh.sagepub.com/content/early/2014/09/08/1049909114548719.abstract>

Noted in Media Watch, 14 February 2011, #188 (p.8):

- *JOURNAL OF NEUROLOGY, NEUROSURGERY & PSYCHIATRY* | Online – 5 February 2011 – '**Palliative care in amyotrophic lateral sclerosis: Review of current international guidelines and initiatives.**' Despite an international consensus that ALS management should adopt a multidisciplinary approach, integration of palliative care into ALS management varies considerably across health care systems. Late referral to palliative services in ALS is not uncommon and may impact negatively on the quality of life of ALS patients and their caregivers. <http://jnnp.bmj.com/content/early/2011/02/04/jnnp.2010.232637.abstract?sid=2fb2379c-b7d2-419d-8a3b-bf6f757148c3>

Reconceptualizing continuing professional development to close long-standing quality gaps in palliative care

AMERICAN JOURNAL OF MEDICAL QUALITY | Online – 10 September 2014 – Reform is fundamentally changing how health care is delivered in the U.S. Increasingly, health care providers are being held accountable for both individual and system performance, making critical reflection, innovation, and care redesign necessary to meet national quality and patient safety goals and standards. Yet amid this progressive environment, some clinical care areas struggle to make meaningful improvements. The reason palliative care has so many enduring quality gaps is widely debated. There is certainly no shortage of best-practice evidence, guidelines, or quality measures for palliative care ... and the research on quality improvement in palliative care is abounding. Yet like many subspecialties, palliative care operates within a complex care system, and long-lasting improvements require trenchant analysis, development, and transformation of care delivery. <http://ajm.sagepub.com/content/early/2014/09/10/1062860614550332.extract>

Of related interest:

- *CA* | Online – 9 September 2014 – '**Patient-centered, evidence-based, and cost-conscious cancer care across the continuum: Translating the Institute of Medicine report into clinical practice.**' The implementation of the recommendations [of the report] in clinical practice will require better patient-clinician communication, improved care coordination, targeted clinician training, effective dissemination of evidence-based guidelines and strategies for eliminating waste, and continuous quality assessment and improvement efforts.¹ <http://onlinelibrary.wiley.com/doi/10.3322/caac.21249/abstract>

1. *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, Institute of Medicine, 2013. http://iom.edu/~media/Files/Report%20Files/2013/Quality-Cancer-Care/qualitycancer-care_rb.pdf

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 8 September 2014 – '**Developing a service model that integrates palliative care throughout cancer care: The time is now.**' The authors identified key elements for models of palliative care in various settings to be potentially equitable, sustainable, feasible, and acceptable, and here we describe a dynamic model for the integrated, simultaneous implementation of palliative care into oncology practice. <http://jco.ascopubs.org/content/early/2014/09/03/JCO.2013.54.8149.abstract>

Cont.

- *SUPPORTIVE CARE IN CANCER* | Online – 7 September 2014 – '**Correlates of a good death and the impact of hospice involvement: Findings from the national survey of households affected by cancer.**' Enhanced provider training/communication, referrals to hospice and greater attention to symptom management may facilitate improved quality of dying. <http://link.springer.com/article/10.1007/s00520-014-2404-z>

The family physician's perceived role in preventing and guiding hospital admissions at the end of life: A focus group study

ANNALS OF FAMILY MEDICINE, 2014;12(5):441-446. Five key roles in preventing and guiding hospital admissions at the end of life were identified: 1) as a care planner, anticipating future scenarios; 2) as an initiator of decisions in acute situations, mostly in an advisory manner; 3) as a provider of end-of-life care, in which competency and attitude is considered important; 4) as a provider of support, particularly by being available during acute situations; and, 5) as a decision maker, taking overall responsibility. Family physicians face many different and complex roles and difficulties in preventing and guiding hospital admissions at the end of life. Enhancing the family physician's role as a gatekeeper to hospital services, offering the physicians more end-of-life care training, and developing or expanding initiatives to support them could contribute to a lower proportion of hospital admissions at the end of life. <http://www.annfammed.org/content/12/5/441.full>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 9 September 2014 – '**The extent and cost of potentially avoidable admissions in hospital inpatients with palliative care needs: A cross-sectional study.**' Of the 99 patients who met the criteria for palliative care need, 22 were deemed to have experienced a potentially avoidable admission. Those living in a residential aged care facility were more at risk of experiencing such admissions. <http://spcare.bmj.com/content/early/2014/09/09/bmispcare-2014-000724.abstract>

Representative sample of articles on avoidable hospital readmissions of hospice or palliative care patients noted in past issues of Media Watch:

- *PALLIATIVE MEDICINE* | Online – 17 February 2014 – '**What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses.**' There are a number of scenarios study participants considered to justify a hospital admission at the end of life: when the patient prefers a hospital admission, when the caring capacity of the care setting is considered to be inadequate and when one of a number of acute medical situations occurs. [Noted in Media Watch, 24 February 2014, #346 (p.12)] <http://pmj.sagepub.com/content/early/2014/02/14/0269216314522317.abstract>
- *JOURNAL OF HOSPITAL MEDICINE* | Online – 14 February 2014 – '**Risk factors for potentially avoidable readmissions due to end-of-life care issues.**' Patients with these risk factors might benefit from palliative care consultation prior to discharge to improve end-of-life care and possibly reduce unnecessary re-hospitalizations. [Noted in Media Watch, 24 February 2014, #346 (p.12)] <http://onlinelibrary.wiley.com/doi/10.1002/jhm.2173/abstract>
- *PALLIATIVE MEDICINE* | Online – 23 December 2013 – '**Economic impact of hospitalisations among patients in the last year of life: An observational study.**' Avoiding these admissions and caring for the patients in alternative locations would save the two hospitals [studied] £5.9 million per year. [Noted in Media Watch, 30 December 2013, #338 (p.12)] <http://pmj.sagepub.com/content/early/2013/12/23/0269216313517284.abstract>

[Media Watch posted on Palliative Care Network-e Website](#)

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

Medical futility and palliative care gain momentum in China

ASIAN BIOETHICS REVIEW, 2014;6(3):315-319. In China, around 160 to 200 million patients are diagnosed with cancer every year, and there are more than 300 million existing cancer patients with an increasing trend of 3% per year. The number of deaths among cancer patients is about 1.4 million per annum. It is important to mention that China has improved the health status of their population by using only 1% of the world's health expenditure, and life expectancy is currently 74 years, one of the best in the world... In almost 60 years, the average life expectancy doubled (from 35 years in 1949 to 74 years in 2011). In Chinese society, the traditional Chinese view of death, the idea of "cherishing life but dreading death" has influenced the attitudes of the public as well as health professionals about end-of-life decision-making and medical futility. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/asian_bioethics_review/v006/6.3.pazooki.html

Using a public health approach to improve end-of-life care: Results and discussion of a health needs assessment undertaken in a large city in northern England

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 5 September 2014 – More people from deprived communities die in hospital. 18% of people who die each year are on a palliative care register, reflecting a lack of recognition and planning for EoLC [end-of-life care] given that 75% of people who die need EoLC. Staff highlighted concerns about capacity of services; pressure on out-of-hospital care; problems at physical and electronic interfaces between services; suboptimal hospital discharge; need for earlier recognition of the EoL stage for patients. Patients and carers stressed the importance of communication, coordination and continuity of care; full involvement in care planning; honesty and support for the bereaved; an advocate for patients and families; accessible information; improved urgent care; integrated team working; pain relief, dignity and respect. <http://spcare.bmj.com/content/early/2014/09/05/bmjspcare-2014-000662.abstract>

End-of-life care in Russia

Palliative medicine: Overview and statistics

БЮЛЛЕТЕНЬ МЕДИЦИНСКИХ ИНТЕРНЕТ-КОНФЕРЕНЦИЙ | Online – Accessed 10 September 2014 – Palliative care developments are now said to be under way, mostly in the hospital context, in all the regions of Russia. Yet the economic constraints of the 1990s have left health services chronically under-funded. In what is the largest geographic country of the world, the combined hospice and palliative care services are currently estimated at around 125 and the challenges are acknowledged as considerable. In 2012 Saratov welcomed the opening of the first and the only regional center of palliative care. This center, however, includes only 15 beds for oncological patients, which does not really meet the requirements of the international standards (10 beds in palliative care center for each 10,000 of population). Palliative care in Russia leaves much to be desired. Poor statistics results from insufficient social concern about people who are left to stand alone in the face of a life-threatening illness. <http://cyberleninka.ru/article/n/palliative-medicine-overview-and-statistics>

N.B. Russian language article.

Noted in Media Watch, 27 August 2012, #268 (p.3):

- **RUSSIA** | *Open Democracy Russia* – 23 August 2012 – **'It's time to stop the suffering.'** In a country with a population of 140 million, there are still no more than a few palliative care initiatives and hardly any palliative care specialists. The Russian Ministry of Health is in the process of developing national regulations and requiring each region to establish a children's hospice or a dedicated hospital palliative care unit. <http://www.opendemocracy.net/od-russia/anna-sonkin/palliative-care-in-russia-its-time-to-stop-suffering>

End-of-life care in Germany

Dying in cancer centers: Do the circumstances allow for a dignified death?

CANCER | Online – 8 September 2014 – In this cross-sectional study, the authors surveyed physicians and nurses in 16 hospitals belonging to 10 cancer centers in Baden-Wuerttemberg, Germany. Half of the participants indicated that they rarely have enough time to care for dying patients, and 55% found the rooms available for dying patients unsatisfactory. Only 19% of respondents felt that they had been well-prepared to care for the dying. Palliative care staff reported much better conditions for the dying than staff from other wards (95% of palliative care staff indicated that patients die in dignity on their ward). Generally, physicians perceived the circumstances much more positively than nurses, especially regarding communication and life-prolonging measures. Overall, 57% of respondents believed that patients could die with dignity on their ward. Only about half of the respondents perceived that a dignified death is possible on their ward. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.28702/abstract>

Noted in Media Watch, 13 January 2014, #340 (p.10):

- *EUROPEAN JOURNAL OF INTERNAL MEDICINE* | Online – 6 January 2014 – '**Trends in specialized palliative care for non-cancer patients in Germany...**' As small steps in the right direction have been taken, integrating PC [palliative care] ideas earlier into treatment of chronic diseases to improve quality of life of NCs [non-cancer patients] during the final stages of their diseases will continue to challenge the health care system in terms of workload, need of more staff, and further training of medical professionals dealing with NCs in the future. [http://www.ejinme.com/article/S0953-6205\(13\)01014-5/abstract](http://www.ejinme.com/article/S0953-6205(13)01014-5/abstract)

Variation in decisions to forgo life-sustaining therapies in U.S. ICUs: Decisions to forgo life-sustaining therapies

CHEST, 2014;146(3):573-582. The magnitude and implication of variation in end-of-life decision-making among ICUs in the U.S. is unknown. The authors reviewed data on decisions to forgo life-sustaining therapy (DFLSTs) in 269,002 patients admitted to 153 ICUs in the U.S. between 2001 and 2009. Patient factors associated with increased odds of DFLST included advanced age, female sex, white race, and poor baseline functional status. Although patient factors explain much of the variability ... significant effects of ICU culture and practice influence end-of-life decision-making. The observation that an ICU's risk-adjusted propensity to withdraw life support is directly associated with its standardized mortality ratio suggests problems with using the latter as a quality measure. <http://journal.publications.chestnet.org/article.aspx?articleID=1830044>

Of related interest:

- *CHEST*, 2014;146(3):532-534. '**Variability in decisions to limit life-sustaining treatment: Is it all about the physician?**' Approximately 20% of deaths in the U.S. occur in or shortly after a stay in the ICU, and the proportion of Medicare beneficiaries who spend time in the ICU in the last 30 days of their lives is increasing. Of the deaths occurring in the ICU, the majority involve decisions to withhold or withdraw life-sustaining treatments. Studies document dramatic variability from ICU to ICU in the proportion of deaths preceded by withholding and withdrawing life-sustaining... <http://journal.publications.chestnet.org/article.aspx?articleid=1900832>



World hospice &
palliative care day

11 October 2014

Who Cares? We Do!

Home page: <http://www.worldday.org/>

Materials: <http://www.worldday.org/materials/>

Integrated care experiences and outcomes in Germany, The Netherlands, and England

HEALTH AFFAIRS, 2014;33(9):1549-1558. This article examines three recent efforts at care coordination that have been evaluated, but not yet included in systematic reviews. The first is Germany's *Gesundes Kinzigtal*, a population-based approach that organizes care across all health service sectors and indications in a targeted region. The second is a program in The Netherlands that bundles payments for patients with certain chronic conditions. The third is England's integrated care pilots, which take a variety of approaches to care integration for a range of target populations. Results have been mixed. Some intermediate clinical outcomes, process indicators, and indicators of provider satisfaction improved; patient experience improved in some cases and was unchanged or worse in others. Across the English pilots, emergency hospital admissions increased compared to controls in a difference-in-difference analysis, but planned admissions declined. Using the same methods to study all three programs, the authors observed savings in Germany and England. <http://content.healthaffairs.org/content/33/9/1549.abstract?=&right>

Of related interest:

- *SOCIAL SCIENCE & MEDICINE* | Online – 11 September 2014 – '**Variation in the costs of dying and the role of different health services, socio-demographic characteristics, and preceding health care expenses.**' [In The Netherlands] the health care costs of population ageing are for an important part attributable to higher mortality rates in combination with high costs of dying. This paper answers three questions that remain unanswered: 1) contributions of different health services to the costs of dying; 2) variation in the costs of dying; and, 3) the influence of preceding health care expenses on the costs of dying. <http://www.sciencedirect.com/science/article/pii/S0277953614005875>

Innovation can improve and expand aspects of end-of-life care in low- and middle-income countries

HEALTH AFFAIRS, 2014;33(9):1612-1619. Provision for end-of-life care around the world is widely variable and often poor, which leads to millions of deaths each year among people without access to essential aspects of care. However, some low- and middle-income countries have improved specific aspects of end-of-life care using innovative strategies and approaches such as international partnerships, community-based programs, and philanthropic initiatives. This article reviews the state of current global end-of-life care and examines how innovation has improved end-of-life care in Nigeria, Uganda, India, Bangladesh, Myanmar, and Jordan. Specifically, we examine how opioids have been made more available for the treatment of pain, and how training and education programs have expanded the provision of care to the dying population. Finally, we recommend actions that policy makers and individuals can take to improve end-of-life care, regardless of the income level in a country. <http://content.healthaffairs.org/content/33/9/1612.short>

Informal caring networks for people at end of life: Building social capital in Australian communities

HEALTH SOCIOLOGY REVIEW | Online – Accessed 13 September 2014 – The care of a person living at home near the end of their life is predominantly provided by family carers with the support of health services such as palliative care. In addition, informal caring networks also contribute at times to the support to the dying person and their carer. In this way, these networks can promote social capital in the communities from which they are drawn. This social approach to end of life care enhances community capacity to provide support to those dying at home and their carers. This article examines relevant published literature to explore the conceptual foundations of informal caring networks, examining the place of social capital and community development in the provision of end of life care at home, particularly in the Australian context. <http://pubs.e-contentmanagement.com/doi/abs/10.5172/hesr.2014.4226>

End-of-life care in India

End-of-life care policy: An integrated care plan for the dying

INDIAN JOURNAL OF CRITICAL CARE MEDICINE, 2014;18(9):615-635. The Indian Society of Critical Care Medicine (ISCCM) published its first guidelines on EOLC [end-of-life care] in 2005, which was later revised in 2012. Since these publications, there has been an exponential increase in empirical information and discussion on the subject. The literature reviewed observational studies, surveys, randomized controlled studies, as well as guidelines and recommendations, for education and quality improvement published across the world. The Indian Association of Palliative Care (IAPC) also recently published its consensus position statement on EOLC policy for the dying. An expert committee of members of the ISCCM and IAPC was formed to make a joint EOLC policy for the dying patients. Proposals from the chair were discussed, debated, and recommendations were formulated through a consensus process. The members extensively reviewed national and international established ethical principles and current procedural practices. This joint EOLC policy has incorporated the socio-cultural, ethical, and legal perspectives, while taking into account the needs and situation unique to India. <http://ijccm.org/article.asp?issn=0972-5229;year=2014;volume=18;issue=9;spage=615;epage=635;aulast=Myatra>

Of related interest:

- *INDIAN JOURNAL OF CRITICAL CARE MEDICINE*, 2014;18(9):560-562. **'Coming together to care for the dying in India.'** Protecting life, ensuring care appropriate to disease prognosis, facilitating a "good death," and alleviating pain, all form a continuum. The guiding principle of medicine has been to care always and cure if possible. <http://ijccm.org/article.asp?issn=0972-5229;year=2014;volume=18;issue=9;spage=560;epage=562;aulast=Mani>

Educating our patients about life and the end of life: Toward a pedagogy of dying

JOURNAL OF THE AMERICAN BOARD OF FAMILY MEDICINE, 2014;27(5):713-716. In this essay, the author suggests that physicians develop a "pedagogy of dying" for their adult patients: educating them about how they can approach death with some measure of grace and dignity, as consistent with their wants as possible, and cognizant of the final reality we all face. This process happens in the ambulatory settings as part of ongoing care and precedes any serious illness or the crisis of hospitalization. He draws on known models for communicating effectively, his own practice experience, and the disciplines of palliative care and bioethics in asking physicians to consider developing such a "pedagogy of dying," a kind of anticipatory guidance toward aging, infirmity, and, ultimately, death. <http://www.jabfm.org/content/27/5/713.full>

End-of-life care in Australia

Forging an advanced practice role for pharmacists in palliative care

JOURNAL OF PHARMACY PRACTICE & RESEARCH | Online – 5 September 2014 – This paper describes the incorporation of an advanced practice pharmacist into a large metropolitan palliative care service. The focus of this appointment has been to develop strategic engagement with primary care providers to better support medicines management for people registered within a metropolitan palliative care service. Through the development of education programs, participation in quality improvement activities and by supporting the ambulatory palliative care team, the advanced practice pharmacist has engaged the community pharmacist as part of the broader palliative care team. There are challenges and opportunities for pharmacists to assist in providing improved palliative care services delivery within the Australian healthcare system. <http://onlinelibrary.wiley.com/doi/10.1002/jppr.1008/abstract;jsessionid=8D6829FD12DB8A8CE5B1064C4EB93AA7.f04t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Cont.

Noted in Media Watch, 25 October 2013, #329 (p.8)::

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 October 2013 – '**Community pharmacists' attitudes toward palliative care: An Australian nationwide survey.**' Pharmacists [i.e., survey respondents] were generally positive about providing services and supports for palliative care patients, yet they also reported negative beliefs and emotions about palliative care. In addition, they had good knowledge of some aspects of palliative care, but misconceptions about other aspects. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0171>

Servicing multi-cultural needs at the end of life

JOURNAL OF RENAL CARE, 2014;40(S1): 6-15. The palliative care movement has taken a leading role in addressing the health and social care needs of patients and families facing the inevitability of death. It has only been recently that attention has focused on the importance of providing care for increasingly diverse societies, for example [in] the U.K. and the U.S. This has now become demographically imperative. When considering these basic and more complex needs of socially diverse populations in the provision of care at the end of life, and during bereavement, we must hold two lenses at the same time; to understand and serve the needs of specific communities requires us to apply a framework of equity of provision. At the same time, however, it is important we do not lose sight of the individuals and families in front of us, whose needs and concerns may not conform to our conscious or unconscious biases. Cross-cultural experiences may also enhance the rich repertoire of the healthcare professional with different and creative ways to ease the dying process for patients, families and staff. Accepting this invitation enables the growth that is the cornerstone of cross-cultural competence and communication skills. At the end of life, an individualised approach to

care with a focus on quality is paramount for any patient, regardless of their ethnic or cultural background. At the end of life, an individualised approach to care with a focus on quality is paramount for any patient, regardless of their ethnic or cultural background. <http://onlinelibrary.wiley.com/doi/10.1111/jorc.12087/full>

Extract from *Journal of Renal Care* article

Each year the number of published indexed [articles] under the headings of "race," "culture" and "ethnicity" on MedLine increases... All these terms have been used to explain patterns of disease, illness experiences, responses to treatment and the use of services. However, substantial problems exist with this burgeoning body of research literature where conceptual sloppiness and semantic confusion are very common. First, researchers rarely define the terms they use... Second, over the years, all terms have been used interchangeably, have been subject to misuse or conflated with other social metrics, for example class or education... This leads to problems with the scientific validity and inevitably bias inferences the results they present. Lastly, the manner in which the categories are used changes due to prevailing fashions and politics...

Of related interest:

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2014;16(7):404-413. '**American Indians' experiences of life-threatening illness and end of life.**' It is taboo to discuss end-of-life care and death. The study focus was identification of tribal values, contributing factors, and decision making regarding end of life. End-of-life experiences for these participants focused on the concept of struggle, coping by seeking knowledge, and applying connectedness to family, community, spirituality, and health care providers. The majority of the participants coped with the struggle through traditional cultural values and ceremonies to reach living. Their culturally ideal end of life was identified as being a proud Indian and living the Indian way of life to the end. http://journals.lww.com/jhpn/Abstract/2014/10000/American_Indians_Experiences_of_Life_Threatening.7.aspx

Cont.

- *JOURNAL OF RENAL CARE*, 2014;40(S1):23-29. '**Communications as care at end of life: An emerging issue from an exploratory action research study of renal end-of-life care for ethnic minorities in the U.K.**' If patients are not fully aware of their condition or of what end-of-life care is, it is less likely that they will be able to be involved in decision-making about their care and this can be compounded where there are communication barriers. Working cross-culturally with diverse populations at end of life requires clinicians and researchers to take a reflective approach to variations in communication about end-of-life care. <http://onlinelibrary.wiley.com/doi/10.1111/jorc.12084/full>

Media Watch Online

International

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

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

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

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

Asia

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

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

Australia

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

Canada

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

ONTARIO | Central Regional Hospice Palliative Care Program: <http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

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

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

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

Europe

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

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

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

A transnational comparison of end-of-life decision making by mature minors

MICHIGAN STATE UNIVERSITY JOURNAL OF MEDICINE & LAW | Online – Accessed 12 September 2014 – Like many Western democracies, Canada's legal regime on minors' entitlements to shape their end-of-life care emphasizes the importance of autonomy. Doing so is consistent with Canada's domestic obligations under its constitution and international obligations under the UN Convention on the Rights of the Child. It is likewise normatively consonant with the broader principle of autonomy underpinning much of international human rights law. It is also, for some Canadians, incongruent with the best interests of the patient. In 2013, a fifteen-year-old boy of south Asian origin came to a Canadian hospital with his parents, complaining of headaches. Tests revealed that the boy had an inoperable brain tumor. Doctors concluded that his condition was terminal. Under Canadian law, he was entitled to shape the tenor of his end-of-life care, including the determination of how aggressively he wanted his medical team to treat his ultimately palliative tumor. His parents, however, wanted to keep his condition a secret and to return him to India for an extended holiday, until his condition could no longer be kept a secret, after which he would pass away in India, surrounded by family. Although the Canadian medical team was uncomfortable with this, it ultimately respected the family's wishes. <https://litigation-essen-tials.lexisnexis.com/webcd/app?action=DocumentDisplay&crawlid=1&doctype=cite&docid=18+Mich.+St.+J.+Med.+%26+Law+139&srctype=smi&srcid=3B15&key=f8a4928c80ead8ab9d6046111f98186>

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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.

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