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.

10 August 2015 Edition | Issue #422



Compilation of Media Watch 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

"General" vs. "specialist" approach to end-of-life care: Scroll down to <u>Specialist Publications</u> and "Resource allocation issues concerning early palliative care" (p.9) in *Annals of Palliative Medicine*.

Canada

Auditor report finds major issues with Manitoba's home care program

MANITOBA | CBC News (Winnipeg) - 5 August 2015 - Winnipeggers are waiting an average of 37 days for home care - a service that's meant to help people stay out of hospitals and personal care homes. The news comes from an auditor general report that made 28 recommended changes to how the province is delivering home care and personal care in Manitoba.¹ Personal care and home care are supposed to help people remain at home rather than staying in hospital or moving more quickly to personal care homes. According to the report, Manitoba's health regions need to pay more attention to how quickly the care is offered and how reliable it is. If the province doesn't do something to address the problem, it could jeopardize the well-being of Manitobans, the report indicated. The audit also found some patient assessments were incomplete and about half of patients weren't reassessed within a year and half, even though that's supposed to happen every year. The regions have also had issues with staffing. The report estimated about \$4 million was spent in two regions on wages for staff when they weren't actually seeing clients, and 16,000 client visits were cancelled because staff were unavailable when they were needed. http://www.cbc.ca/news/canada/manitoba/au ditor-report-finds-major-issues-withmanitoba-s-home-care-program-1.3180343

Specialist Publications

'Early palliative care and its translation into oncology practice in Canada: Barriers and challenges' (p.8), in *Annals of Palliative Medicine.*

1. 'Manitoba Home Care Program,' Office of the Auditor General Manitoba, July 2015. <u>http://www.oag.mb.ca/wp-content/uploads/2015/08/Manitoba-Home-Care-Program-Report-Web-Version.pdf</u>

N.B. In response to the auditor general's report, Health Minister Sharon Blady announced that she has created a new home care 'leadership team' to delve into the issues raised by the report. Palliative care services were not included in the auditor general's report (see 'More palliative care services needed in Manitoba, some help on way,' CBC Radio News, 23 April 2015, noted in Media Watch, 27 April 2015, #407 (p.1)).

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

California's baby boom will become a senior boom

CALIFORNIA | *The Sacramento Bee* – 6 August 2015 – Although its overall population growth continues to slow, California's senior population – those 65 and older – will nearly double in the next 15 years, a new report concludes.¹ Coincidentally, the California HealthCare Foundation also released a report about the adequacy of medical care for the state's rising senior population.² It concluded that while the increasing population will increase demands on services, the impacts will vary by service type and region. <u>http://www.sacbee.com/news/politics-government/capitol-alert/article30337752.html</u>

- 1. 'Planning for California's Growing Senior Population,' Public Policy Institute of California, August 2015. <u>http://www.ppic.org/main/publication_quick.asp?i=1156</u>
- 'Beds for Boomers: Will California's Supply of Services Meet Senior Demand?' California HealthCare Foundation, August 2015. <u>http://www.chcf.org/publications/2015/08/beds-forboomers? cldee=ZHdhbHRlcnNAc2FjYmVILmNvbQ%3d%3d</u>

Report says New York State falls short on palliative care...

STATE OF NEW YORK | WXXI Public Broadcasting Council (Rochester) - 6 August 2015 - According to a report by the American Cancer Society, New York State needs to do more to give cancer patients better access to palliative care.¹ Bill Sherman, vice president for government relations for the Eastern Division of the Cancer Action Network, says many people believe palliative care is for the end of life, but it can benefit patients at any stage of a disease ... [and] ... palliative care also lowers health care costs by reducing redundancies in treatment. "On average, through palliative care, we can save between \$1,700 and \$10,000 per patient. An average academic medical center ... can save \$2.4 million per year using palliative care." The American Cancer Society recommends that the New York State Department of Health develop a campaign to educate the public about palliative care and a patient's rights to receive it. The organization is also recommending palliative care training for health care providers and continued access to pain therapies, including prescription opioids that are at the center of a state wide and national addiction epidemic. <u>http://wxxinews.org/post/report-</u> <u>says-nys-falls-short-palliative-care-tobacco-</u> <u>cessation</u>

American Cancer Society report

'How Do You Measure Up?' measures state policies and provides a blueprint for effective legislation on six priority areas: 1) Breast and cervical cancer early detection program funding; 2) Access to care for the uninsured; 3) Colorectal screening coverage laws; 4) Smoke-free laws; 5) Tobacco prevention program funding; and, 6) Tobacco taxes. Nearly half of all states are falling short on legislative solutions to prevent and fight cancer. The report also provides an overview of how passage of the new health care law, the Affordable Care Act, will dramatically change the landscape of state health policy in the coming years.

N.B. See pp.40-42, 'Palliative Care Across the U.S.

 'How do you measure up? A Progress Report on State Legislative Activity to Reduce Cancer Incidence and Mortality,' American Cancer Society, 2015. <u>http://www.acscan.org/content/wpcontent/uploads/2015/08/HDYMU-2015.pdf#page=17</u> Of related interest:

- FORBES | Online 6 August 2015 'Dying to live: Why is health care so valuable in the face of death?' Care near the end of life or for life-threatening illnesses is often highly valued by patients but fares poorly with past and recent valuation frameworks constructed by buyers of such care. This has recently become the source of much debate in cancer care, where treatments for metastatic disease may offer limited survival benefits at high costs. Traditional valuation frameworks, however, fail to account for the unique value dimensions in this type of care. http://www.forbes.com/sites/tomasphilipson/2015/08/06/dying-to-live-why-is-health-care-so-valuable-in-the-face-of-death/
- STATELINE (The Pew Charitable Trusts) | Online 5 August 2015 'In 40 states, a new focus on end-of-life care and counseling.' Beginning next year, the federal government will conduct a five-year, 40-state experiment to determine whether there is a better way to help elderly Americans come to grips with terminal illnesses and prepare to die. Last month, the Obama administration announced that 141 hospices across the country will offer end-of-life care and counseling to dying Medicare patients at the same time those patients receive treatment to extend their lives. Currently Medicare, the federal health insurance system for people older than 65 or with certain disabilities, requires terminally ill patients to choose one or the other. Hospice services typically involve a team of doctors, nurses, social workers, bereavement counselors, aides and volunteers who address the physical, social, emotional and spiritual needs of dying patients and their families. The hope is that by allowing people to pursue both paths, more will opt to receive hospice services that will improve the quality of their remaining days and reduce the cost of end-of-life care. If the experiment is successful, it likely will lead to a similar shift by Medicaid, the joint federal-state health insurance program for the poor, and by private insurers. http://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2015/08/05/in-40-states-anew-focus-on-end-of-life-care-and-counseling

Noted in Media Watch, 27 July 2015, #420 (pp.4-5):

THE NEW YORK TIMES | Online – 22 July 2015 – 'Medicare to try a blend of hospice care and treatment.' Most older Americans close to death have to make a difficult choice: to continue with traditional medical treatment or switch to hospice care, which focuses not on a cure but on easing their remaining days. Now, Medicare is testing a third alternative: both. http://www.nytimes.com/2015/07/22/upshot/medicare-to-try-a-blend-of-hospice-care-and-treatment.html? r=0&abt=0002&abg=1

People are developing dementia earlier and dying of it more, a study shows

THE WASHINGTON POST | Online – 6 August 2015 – People are developing dementia a decade before they were 20 years ago, perhaps because of environmental factors such as pollution and the stepped-up use of insecticides, a wide-ranging international study has found.¹ The study ... found that the disease is now being regularly diagnosed in people in their late 40s and that death rates are soaring. The problem was particularly acute in the U.S., where neurological deaths in men aged over 75 have nearly tripled and in women risen more than fivefold. https://www.washingtonpost.com/world/people-are-developing-dementia-earlier-and-dying-of-it-more-a-study-shows/2015/08/06/599b16b8-3c0a-11e5-8e98-115a3cf7d7ae story.html

1. 'Neurological deaths of American adults (55-74) and the over 75's by sex compared with 20 Western countries 1989-2010: Cause for concern,' *Surgical Neurology International*, July 2015. <u>http://surgicalneurologyint.com/surgicalint_articles/neurological-deaths-of-american-adults-55-74-and-the-over-75s-by-sex-compared-with-20-western-countries-1989-2010-cause-forconcern/</u>

Media Watch: Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

Investigational drug use in terminal illness

New law gives patients "right to try"

MINNESOTA | The Post Bulletin (Rochester) - 3 August 2015 - Patients with a terminal illness will have more access to experimental drugs thanks to a new law that took effect in Minnesota during the weekend. The "Right to Try Act" ... allows individuals with a terminal illness to use investigational drugs or devices that have cleared phase 1 of a clinical trial, but have not been approved for general use by the federal Food & Drug Administration (FDA). More than twenty states nationwide have "right to try" laws on the books. The law does require a doctor's prescription in order for the patient to use an investigational drug. It also provides legal protections for a doctor who prescribes such a drug to a patient. Absent from the law are any mandates requiring doctors to write prescriptions for these drugs, pharmaceutical companies to provide them or for insurance companies to cover the cost of them. Some people have raised safety concerns surrounding the idea of allowing patients to access drugs that haven't won FDA approval. http://www.postbulletin.com/news/politics/pol itical-notebook-new-law-gives-patients-right-to-try/article_7f99bbd3-8f23-5097-a646-a57f4868d364.html

Specialist Publications

'Questions of safety and fairness raised as right-to-try movement gains steam' (p.12), in *Journal of the American Medical Association.*

Noted in Media Watch, 19 January 2015, #393 (p.2):

THE NEW YORK TIMES | Online – 10 January 2015 – 'Patients seek "right to try" new drugs.' Since May, a string of states have passed laws that give critically ill patients the right to try medications that have not been approved by the FDA. Deemed "right to try" laws, they have passed quickly and often unanimously in Colorado, Michigan, Missouri, Louisiana and Arizona... The laws do not seem to have helped anyone obtain experimental medicine, as the drug companies are not interested in supplying unapproved medications outside the supervision of the FDA. Legislators in 10 other states will introduce these bills in 2015 ... and lawmakers in Kansas, Tennessee, Texas and Wyoming have already filed bills or announced intentions to do so. Critics of the laws ... call them "a cruel sham." <u>http://www.nytimes.com/2015/01/11/us/patients-seek-right-to-try-new-drugs.html?ref=health& r=0</u>

Downside of life-prolonging technology

The device kept him alive, but was the pain and suffering worth it?

THE WASHINGTON POST | Online – 3 August 2015 – In countries such as the U.S. with ready access to new technologies, many patients have the attitude that if something can save you, why not try it? Opting out of available treatment is often seen as giving up. And doctors might equate non-intervention on their part to failure to help a patient. Discussing other options can be difficult. A [2014] study¹ ... said that 52% of surveyed heart-failure clinicians reported feeling reluctant to discuss end-of-life options with patients, citing their own discomfort as well as the belief that patients would feel uncomfortable with the subject. Other respondents said that they didn't want to make the family lose hope. http://www.washingtonpost.com/national/health-science/the-device-kept-him-alive-but-was-the-pain-and-suffering-worth-it/2015/08/03/8c140298-2bfd-11e5-bd33-395c05608059 story.html

1. 'Doctors reluctant to discuss end-of-life care with heart failure patients,' 2014 Quality of Care & Outcomes Research Scientific Sessions <u>http://blog.heart.org/doctors-reluctant-to-discuss-end-of-life-care-with-heart-failure-patients/</u>

N.B. The article was excerpted from 'A failing heart and the downside of life-prolonging technology,' *Health Affairs*, 2015;34(8):1418-1422: <u>http://content.healthaffairs.org/content/34/8/1418.full</u>

Death midwives, home funeral advocates push to take care of loved ones after they die

ILLINOIS | *The Northwest Herald* (Crystal Lake) – 2 August 2015 – [Laura Fry] is part of a fledgling nationwide movement trying to reclaim care for the dying and the dead. Death midwives and proponents of home funerals strive to remove some of the business-minded aspects of death. Akin to the home birth movement of the 1980s, advocates say dying and the hours or days afterward should be a personal, intimate experience people are allowed to have at home. As opposed to a traditional funeral that entails a family relinquishing their loved one to a funeral home, a home funeral allows keeping someone home for one to three days after they die... In many cases, the family bathes and dress as their dead loved one, anoints them with oils and prays over them before the person is buried or cremated. Another factor is cost. According to the Illinois Funeral Director's Association, a traditional funeral averages about \$7,000. A home funeral can cost \$200. http://www.nwherald.com/2015/07/31/death-midwives-home-funeral-advocates-push-to-takecare-of-loved-ones-after-they-die/an7t8p5/

Noted in Media Watch, 28 March 2011, #194:

TENNESSEE | The Commercial Appeal (Memphis) – 26 March 2011 – 'Home funerals a spiritually fulfilling option for families.' When a loved one dies, most of us assume the body must be embalmed and set in a metal casket inside a concrete vault for burial. Not true. Those are options, not legal requirements. Embalming is not required in any state... Neither a casket nor a vault is a legal requirement. Licensed morticians are not required to transport a body. And home funerals are legal in Tennessee, Arkansas, Mississippi and more than forty other states. http://www.commercialappeal.com/news/2011/mar/26/guest-commentary-home-funerals-a-spiritually-for/

New pediatric resource helps focus attention on children's unmet needs

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 30 July 2015 – 'Facts & Figures: Pediatric Palliative & Hospice Care in America' provides insight into the care needs of young people who might benefit from pediatric palliative/hospice care (PP/HC). These are children with chronic, complex, and/or life-limiting conditions. The report can help hospice and palliative care providers – as well as policymakers, funders and the news media – to better understand both the current challenges and also the unmet needs of children and their families across the country. The U.S. Department of

Noted in Media Watch, 6 July 2015, #417 (p.10):

Health & Human Services reports that the number of children with special health care needs is increasing; 15.1% of U.S. children ages 0-17 (11.2 million) are in this category. http://www.nhpco.org/sites/default/files/publi c/quality/Pediatric Facts-Figures.pdf

Specialist Publications

'Priorities for global research into children's palliative care: Results of an International Delphi Study' (p.13), in *BMC Palliative Care*.

 CLINICAL PEDIATRICS | Online – 26 June 2015 – 'Where children die: Obstacles to quality end-of-life care.' Fifty thousand children die annually in the U.S., and 500,000 more live with chronic diseases. After accidental/unanticipated mortalities, 5% of childhood deaths are secondary to cancer and 16% more to other chronic conditions ages 0-24 years. The authors discuss how and where pediatric patients die in America and identify deficiencies in their end-of-life care... http://cpj.sagepub.com/content/early/2015/06/24/0009922815591891.extract

Media Watch: Back Issues

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- STATE OF WASHINGTON | The Columbian 6 August 2015 'Death with dignity participation rises in Washington.' More terminally ill patients ... received prescriptions to end their lives in 2014 than in previous years.¹ Washington's Death with Dignity Act allows adults in the state with six months or less to live to request lethal doses of medication from a physician. Last year, 176 people ... received prescriptions for lethal doses of medication up about 2% from the previous year. Of those who received the medication, 170 are known to have died... The health department received confirmation 126 of those who died did ingest the lethal medication. Seventeen did not ingest the medication and the ingestion status is unknown for 27 people. http://blogs.columbian.com/healthbeat/2015/08/06/death-with-dignity-participation-rises-in-washington/
 - 1. 'Washington State Department of Health 2014 Death with Dignity Act Report: Executive Summary,' Washing State Department of Health, Accessed 7 August 2015 <u>http://www.doh.wa.gov/portals/1/Documents/Pubs/422-109-DeathWithDignityAct2014.pdf</u>

International

Elder Care in Australia

Inquiry to investigate how aged care residents will fare without registered nurses on duty 24/7

AUSTRALIA (New South Wales) | ABC News – 4 August 2015 – An inquiry will examine how New South Wales' most vulnerable aged care residents will fare in a future without registered nurses on duty at all times. Last year there were moves to drop the requirement from the New South Wales (NSW) Health Act as a result of changes to the Federal Aged Care Act. The NSW Government decided instead to maintain the status quo until the end of 2015 to allow more consultation. A State Parliamentary Committee begins hearing submissions on how having RNs on duty 24/7 in high-needs facilities affects quality of life and care. http://www.abc.net.au/news/2015-08-05/inquiry-aged-care-residents-no-registered-nurses-all-shifts/6672340

End-of-life care in England

New National Health Service death guidelines "worse than Liverpool Care Pathway"

U.K. (England) | *The Daily Telegraph* – 3 August 2015 – New guidelines on "end-of-life" care are worse than The Liverpool Care Pathway and could push more patients to an early grave, a leading doctor has warned.¹ Professor Patrick Pullicino, one of the first medics to raise concerns over the pathway, said the [new] national proposals would encourage hospital staff to guess who was dying, in the absence of any clear evidence, and to take steps which could hasten a patients' death. The Liverpool Care Pathway (LCP) ... was officially phased out last year... Last week the National Institute of Health & Care Excellence (NICE) published guidance for hospital staff on end-of-life care. Writing for *The Daily Telegraph*, Pullicino said that the plans repeat features of the pathway which made it so dangerous, compounding them with even more lethal errors.² http://www.telegraph.co.uk/news/health/news/11779213/New-death-guidelines-worse-than-Liverpool-Care-Pathway.html

 'Care of the Dying Adult: Draft Guideline Consultation,' National Institute for Health & Care Excellence (NICE), 30 July 2015. (Consultation process will close 9 September 2015, Anticipated publication date December 2015) [Noted in Media Watch, 3 August 2015, #421 (p.5)] http://www.nice.org.uk/guidance/indevelopment/GID-CGWAVE0694/consultation/care-of-the-dying-adult-draft-guideline-consultation

Cont.

2. 'The new end-of-life guidelines are lethal,' The Daily Telegraph, 3 August 2015. Diagnosis of who was imminently dying was the core problem of the LCP and is no better in the NICE document. It includes a cookbook list of features that may suggest someone is dying, but is totally inadequate to make a diagnosis and is not evidence-based. We are back at the LCP in terms of the risk of putting patients who are not dying onto inappropriate and potentially lethal treatment. http://www.telegraph.co.uk/news/nhs/11779394/The-new-end-of-life-guidelines-are-lethal.html

Of related interest:

- U.K. (England) | *The North Devon Gazette* 6 August 2015 'Hospice funding "frozen" as demand increases.' North Devon Hospice said its grant had been frozen for nearly 10 years and it received less than the national average for U.K. hospices. The hospice, which costs nearly £5 million to run and cares for more than 3,000 people every year, receives just 21% of its funding from National Health Service Northern, Eastern & Western Devon Clinical Commissioning Group. Children's Hospice South West has received the same level of funding since 2010 a contribution of around eight 8% of the charity's £8 million annual total costs. More than two thirds of U.K. hospices had statutory funding frozen or slashed in 2014/2015¹ http://www.northdevongazette.co.uk/news/hospice_funding_frozen_as_demand_increases 1_4 183616
 - 'Commissioning and statutory funding arrangements for hospices in England: Survey 2015,' Hospice UK and Together for Short Lives. [Noted in Media Watch, 20 July 2015, #419 (p.6). <u>http://www.togetherforshortlives.org.uk/assets/0001/1502/Hospice_commissioning_and_fun_ding_survey_results_2015.pdf</u>

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.

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.

2. Links often remain active, however, for only a limited period of time.

3. Access to a complete article, in some cases, may require a subscription or one-time charge.

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

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

Something Missed or Overlooked?

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

Media Watch: Palliative Care Network-e Website

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

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

Palliative and end-of-life care for newborns and infants

ADVANCES IN NEONATAL CARE, 2015;15(4):239-240. The changes in this revised statement [i.e., position paper¹] reflect how we now view palliative care. Sixteen clinical recommendations span identification of eligible infants before and after birth, delineate components of a palliative care program, and discuss emotional support for parents, families, and health care providers. http://journals.lww.com/advancesinneonatalcare/Citation/2015/08000/Palliative and End of Life Care for Newborns and.5.aspx

1. 'Palliative and End-of-Life Care for Newborns and Infants,' National Association of Neonatal Nurses, February 2015. <u>http://www.nann.org/uploads/files/PalliativeCare6_FINAL.pdf</u>

Noted in Media Watch, 29 December 2014, #390 (pp.9-10):

- INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2014;20(3):143-148. 'Perinatal palliative care: A developing specialty.' Neonates and babies have the highest death rate in the paediatric population. Perinatal palliative care aims to enhance the quality of life of babies with a life-limiting condition and their families. However, very little data is available on perinatal palliative care and its impact on babies and families along their journey. End-of-life decision-making for babies with an adverse prognosis also remains ethically challenging. This paper provides an overview of perinatal palliative care and its development, and then considers some of the issues affecting this field by looking at single national, institutional, and patient case studies. http://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2014.20.3.143
- MCN, AMERICAN JOURNAL OF MATERNAL CHILD NURSING, 2015;40(1):44-50. 'Clinician perspectives of barriers in perinatal palliative care.' [Among the study participants] nurses expressed more obstacles at the healthcare systems level, reporting difficulty in their ability to garner interdisciplinary support and gain administrative backing. Physicians are more confident in their ability to counsel patients than nurses. Both expressed similar feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. Participants in the study also reported a lack of societal support and understanding about perinatal palliative care. http://journals.lww.com/mcnjournal/Abstract/2015/01000/Clinician Perspectives of Barriers in Perinatal.8.aspx

Early palliative care and its translation into oncology practice in Canada: Barriers and challenges

ANNALS OF PALLIATIVE MEDICINE, 2015;4(3):135-149. Key clinical practice guidelines have influenced, and have been translated into, Canadian oncology policy and operations. Comprehensive accreditation standards exist to guide practice in institutional and ambulatory care settings. Barriers and challenges: 1) Education and attitudes; 2) Compassion fatigue; 3) Terminology; 4) Paucity of research; 5) Aggressive cancer care; and, 6) Organization and operational considerations. Eight made-in-Canada innovations emerged and are described. Lessons learned and recommendations describe a plan for action. http://www.amepc.org/apm/article/view/6748

N.B. To access the complete article without cost, click on 'PDF.'

Noted in Media Watch, 3 August 2015, #421 (p.12):

 SUPPORTIVE CARE IN CANCER | Online – 31 July 2015 – 'Implementation of National Comprehensive Cancer Network Palliative Care Guidelines by member institutions.' As part of an effort to improve the palliative care (PC) of cancer patients, the [U.S.] National Comprehensive Cancer Network has developed clinical practice guidelines that promote access to quality, evidence-based PC. <u>http://link.springer.com/article/10.1007/s00520-015-2862-y</u>

N.B. Selected articles on the integration of early palliative care with oncology care noted in past issue of Media Watch are listed in the issues of the weekly report of 30 March 2015, #403 (pp.15-16) and 22 December 2014, #389 (pp.14-15).

Resource allocation issues concerning early palliative care

ANNALS OF PALLIATIVE MEDICINE. 2015: 4(3):156-161. This article discusses economic considerations associated with different concepts of early palliative care (ePC). The specialist approach: The most frequently cited ePC trials examine the concurrent provision of specialist palliative care in addition to routine care. Most of this specialist palliative care has been provided by multi-professional teams in an outpatient setting of tertiary care centers. A number of research groups have also provided data about the resource utilizations of this approach. From this, a rough estimate of the cost of early specialist palliative care can be derived. Yet, in many parts of North America, Europe and other regions, funding for such outpatient specialist palliative care is non-existent. Recent studies have pointed out that ePC for inpatients is associated with cost savings. These cost savings are even more pronounced the earlier specialist palliative care is integrated in the care for the patients. Strengthening of general palliative care: Most institutions recommend palliative care as an approach should be strengthened as a part of standard care. To accomplish this different measures such as teaching of general palliative care competencies of oncology teams, routine symptom assessment, or the mandatory implementation of advanced care planning in care trajectories, are being promoted. Due to the heterogeneity of these approaches, cost calculations are difficult, but can be weighed against cost-savings associated with, for example, less utilization of futile diagnostic and therapeutic procedures. Researchers, health care providers and policy makers need to distinguish the different concepts behind ePC before providing cost estimates. http://www.amepc.org/apm/article/view/6882

Extract from Annals of Palliative Medicine article

From the authors' view, it is evident that neither of the two approaches (general vs. specialist) can be a one-or-the-other choice. Successful ePC will most likely rely on a joint effort of all medical disciplines and professions in close cooperation and early integration of specialist PC services.

N.B. To access the complete article without cost, click on 'PDF.'

Incorporation of life expectancy estimates in the treatment of palliative care patients receiving radiotherapy: Treatment approaches in light of incomplete prognostic models

ANNALS OF PALLIATIVE MEDICINE, 2015;4(3):162-168. Physician estimates of patients' survival times have historically been inaccurate. In particular, physicians have often been overly optimistic in their predictions. The authors' review begins by documenting some of the literature addressing these concerns and proceeds to a discussion of prognostic models that have been created to aid physicians in providing more accurate estimates. They then discuss new findings showing survival to be influenced by particular treatment factors. Given such findings, currently existing prognostic models are now incomplete. http://www.amepc.org/apm/article/view/7035

N.B. To access the complete article without cost, click on 'PDF.'

Noted in Media Watch, 8 June 2015, #413 (p.8):

- U.K. | *The Guardian* 2 June 2015 'Why doctors get it wrong about when you will die.' In one of the largest systematic reviews of survival predictions in terminally ill patients with cancer, predictions were correct to within one week in 25% of cases, correct to within two weeks in 43%, and correct to within four weeks in 61%. Doctors tended to overestimate survival.' http://www.theguardian.com/lifeandstyle/2015/jun/02/doctors-predict-patient-die-prognosis-wrong
 - 1. 'A systematic review of physicians' survival predictions in terminally ill cancer patients,' *British Medical Journal*, 24 July 2003. <u>http://www.bmj.com/content/327/7408/195</u>

End-of-life care in Australia

End-of-life care practices of critical care nurses: A national cross-sectional survey

AUSTRALIAN CRITICAL CARE | Online – 28 July 2015 – Analysis identified six domains of endof-life care practice: 1) Information sharing; 2) Environmental modification; 3) Emotional support: 4) Patient and family centred decision-making; 5) Symptom management; and, 6) Spiritual support. Statistics identified a high level of engagement in information sharing and environmental modification practices and less frequent engagement in items from the emotional support and symptom management practice areas. The findings of this study identified domains of end-of-life care practice, and critical care nurse engagement in these practices. Findings highlight future training and practice development opportunities, including the need for experiential learning targeting the emotional support practice domain. <u>http://www.australiancriticalcare.com/article/S1036-7314(15)00076-4/abstract</u>

The nature of death, coping response and intensity of bereavement following death in the critical care environment

AUSTRALIAN CRITICAL CARE, 2015;28(2):64-70. The results from this evaluation provide insight into the impact of bereavement after death in the critical care environment and inform potential preventative approaches at the time of death to reduce bereavement intensity. At 6 months, variables significantly associated with bereavement intensity were: 1) Being unprepared for the death; 2) A drawn out death; 3) A violent death; and, 4) If the deceased appeared to suffer more than expected. Analysis revealed being unprepared for the death appears to account for these relationships. Regarding coping, there were significant increases from 3 to 6 months in both acceptance scales and planning on The Brief COPE Inventory. Greater use of emotional support, self-blame, and denial were multivariate variables associated with higher bereavement intensity at 6 months. http://www.australiancriticalcare.com/article/S1036-7314(15)00036-3/abstract

N.B. The Brief COPE Inventory: http://www.psy.miami.edu/faculty/ccarver/sclCOPEF.html

Of related interest:

- OMEGA JOURNAL OF DEATH & DYING | Online 6 August 2015 'Examining linkages between bereavement grief intensity and perceived death quality: Qualitative findings.' Bereavement was found to be an individualized, contextualized, and multifaceted experience, but with three themes emerging: 1) The huge loss and enormous gap in life as a result of the death of a loved one; 2) Extreme acute grief; and, 3) The uncertain step-laddered journey of grieving to bereavement recovery. This recovery is impacted by both good and bad aspects of the death or dying process, as well as good and bad after-death events and developments. http://ome.sagepub.com/content/early/2015/08/05/0030222815598442.abstract
- OMEGA JOURNAL OF DEATH & DYING | Online 4 August 2015 'A new state of being: The lived experience of parental bereavement.' In spite of growing bereavement literature, the meaning of the lived experience of parental bereavement is not well understood. [In this study] the nature of parental bereavement was revealed to be a new state of being into which parents enter immediately after the death of a child and which has no end point. http://ome.sagepub.com/content/early/2015/08/04/0030222815598455.abstract
- OMEGA JOURNAL OF DEATH & DYING | Online 4 August 2015 'Preliminary evaluation of a prolonged grief questionnaire for adolescents.' A new measure was designed based on the Extended Grief Inventory, the Inventory of Complicated Grief Revised for Children, and the Inventory of Prolonged Grief for Children/Adolescents. Analysis revealed item loadings on two factors, which the authors named separation distress and secondary emotions. The small sample size is a major limitation. However, the Prolonged Grief Questionnaire for Adolescents may be a promising tool for assessing prolonged grief symptoms in adolescents. http://ome.sagepub.com/content/early/2015/08/04/0030222815598046.abstract

A "good death" with irreversible liver disease: Talking with patients and families about deteriorating health and dying

CLINICAL LIVER DISEASE, 2015;6(1):15-18. Patients with irreversible, advanced liver disease and their families live with a complex and challenging condition that follows a highly unpredictable illness trajectory. As their health deteriorates, patients often experience debilitating symptoms, psychological stress, family worries, financial problems, social stigma, and existential distress. In addition, there is the ever-present threat of acute, life-threatening complications. Treatment of these episodic decompensations leads to recurrent hospitalizations and difficult decisions about how and where a patient might choose to die. Liver transplantation can be life-saving, but patients have to be "sick enough to die" to be accepted onto a transplant list. Then, patients and their families have to cope with the uncertainty of whether they will ever be able to receive a transplant and live, or will in fact die. <u>http://onlinelibrary.wiley.com/doi/10.1002/cld.479/full</u>

N.B. The theme of this issue of *Clinical Liver Disease* is 'The Future in Liver Medicine & Palliative Care.' Journal contents page: <u>http://onlinelibrary.wiley.com/doi/10.1002/cld.v6.1/issuetoc</u>

Advance directives in some Western European Countries: A legal and ethical comparison between Spain, France, England, and Germany

EUROPEAN JOURNAL OF HEALTH LAW, 2015;22(4):321-345. The authors studied national laws on advance directives in various Western European countries: Romance-speaking countries (Italy, France, Portugal, and Spain), English-speaking countries (Ireland and the U.K.), and German-speaking countries (Austria, Germany, and Switzerland). They distinguish two potentially complementary types of advance medical declaration: the "living will" and the nomination of a legal proxy. After examining the similarities and differences between countries, the authors analyse the legislation of four countries (Spain, France, England, and Germany), since the other countries in this survey have similar legal principles and/or a similar political approach. In all the countries examined, advance directives have been seen as an instrument to enable the patient's right to self-determination. Notwithstanding, in Romance-speaking countries, the involvement of physicians in the end-of-life process and risks arising from the execution of advance directives were also considered. <u>http://booksandjournals.brillonline.com/content/journals/10.1163/15718093-12341368</u>

Of related interest:

- ANNALS OF AMERICAN THORACIC SOCIETY | Online 4 August 2015 'Prior advance care planning is associated with less decisional conflict in surrogates for the critically ill.' [In this study] moderate or high levels of decisional conflict were present in 48% of [the 471] surrogates [representing 257 patients]. Surrogates who had engaged in prior advance care planning conversations had significantly lower levels of decisional conflict compared to those who had not. These results suggest that the scope of benefit of advance care planning may extend beyond respecting patients' wishes to also ameliorate the burden placed on patients' loved ones who act as surrogates. http://www.atsjournals.org/doi/abs/10.1513/AnnalsATS.201504-2530C#.VcHoH_9RGos

Cont.

- BMC PALLIATIVE CARE | Online 1 August 2015 'Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: A qualitative study.' Establishing a concordant relationship, based on negotiated understanding of shared perspectives, can help to improve communication between healthcare professionals and family carers of their patients. [This study demonstrated that] carers' experience of the end-of-life care of their relative was enhanced when mutual understanding was achieved with healthcare professionals. However, some carers reported communication to be ineffective. http://www.biomedcentral.com/content/pdf/s12904-015-0032-0.pdf
- MEDICAL DECISION MAKING | Online 5 August 2015 'Does shared decision making in cancer treatment improve quality of life? A systematic literature review.' There is weak evidence that aspects of shared decision-making approaches are positively associated with quality of life outcomes and very little evidence of a negative association. The extant literature largely assessed patient involvement, only capturing one aspect of the shared decision-making construct, and is of poor quality, necessitating robust studies examining the association. http://mdm.sagepub.com/content/early/2015/08/04/0272989X15598529.abstract
- OMEGA JOURNAL OF DEATH & DYING | Online 6 August 2015 'Association between attitude toward death and completion of advance directives.' Among individuals who did not consider themselves religious, the mean death avoidance attitude scores differed significantly among those with advance directives and those without, as did the mean approach acceptance attitude scores of those with advance directives and those without. http://ome.sagepub.com/content/early/2015/08/05/0030222815598418.abstract

Questions of safety and fairness raised as right-to-try movement gains steam

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 5 August 2015 – A patient's right to try an investigational drug is at the core of right-to-try laws ... which the libertarian [Arizona-based] Goldwater Institute has championed. Such laws allow patients with terminal illnesses, with their physician's consent, to request drugs that have undergone phase 1 clinical safety testing directly from pharmaceutical manufacturers, instead of applying through the Federal Drug Administration's (FDA's) expanded access program. The Institute became interested in the topic while researching the FDA's policy on emerging medical technologies. The institute heard stories about how time-consuming it was for physicians to complete the expanded access form, as well as the 2 to 4 months that it often took for such requests to be approved, explained Kurt Altman, the institute's director of national affairs and special counsel. Yet bioethicists question whether such laws offer anything more than "the creation of false hope."¹ Individual patients with a serious or life-threatening illness can already request investigational drugs through the FDA's expanded access program. <u>http://jama.jamanetwork.com/article.aspx?articleid=2424669</u>

 'Should patients in need be given access to experimental drugs?' *Expert Opinion on Pharmaco-therapy*, 2015;16[9]:1275-1279. The authors discuss the impulse to rescue individual patients facing dire diseases and underscore the ethical questions that such rescue efforts raise. http://informahealthcare.com/doi/pdf/10.1517/14656566.2015.1046837

Exploring the management of death: Emergency nurses' perceptions of challenges and facilitators in the provision of end-of-life care in the emergency department

JOURNAL OF EMERGENCY NURSING | Online – 30 July 2015 – High scores on the quantitative survey showed a high mean level of consistently positive attitudes and beliefs toward caring for dying patients, and their families and loved ones. Analysis of the focus group transcripts uncovered nine themes, reflecting concerns around comfort and challenges with end-of-life (EOL) care, appropriate training for nurses, and the availability of resources to provide this type of care in the emergency setting. Emergency nurses are comfortable providing EOL care in the emergency setting, but note that challenges to providing good care include lack of space, time, and staff. Other challenges involve the mismatch between the goals of emergency care and those of EOL care, as well as the emotional burden of caring for the dying, especially when the appropriate resources are lacking. <u>http://www.jenonline.org/article/S0099-1767(15)00229-9/abstract</u>

Noted in Media Watch, 9 February 2015, #396 (p.11):

PALLIATIVE MEDICINE | Online – 29 January 2015 – 'What's in a name? A qualitative exploration of what is understood by "palliative care" in the emergency department.' There are entrenched contradictions and tensions surrounding the term "palliative care"; confronting these is likely to require more than re-branding, and will promote better care for this vulnerable patient group... <u>http://pmj.sagepub.com/content/early/2015/01/23/0269216314560801.abstract</u>

Noted in Media Watch, 18 August 2014, #371 (p.12):

PALLIATIVE MEDICINE | Online – 12 August 2014 – 'What is the incidence of patients with
palliative care needs presenting to the emergency department? A critical review.' There is
an absence of evidence regarding the incidence of patients with palliative care needs presenting to the emergency department. Further research needs to be undertaken in this area to ensure both clinicians and policymakers have sufficient information for service provision.
http://pmj.sagepub.com/content/early/2014/08/07/0269216314543318.abstract

Laying futility to rest

JOURNAL OF MEDICINE & PHILOSOPHY | Online – 1 August 2015 – The author examines the formal structure of the concept of futility, enabling identification of the appropriate roles played by patient, professional, and society. He argues that the concept of futility does not justify unilateral decisions to forego life-sustaining medical treatment over patient or legitimate surrogate objection, even when futility is determined by a process or subject to ethics committee review. Furthermore, the author argues for a limited positive ethical obligation on the part of health care professionals to assist patients in achieving certain restricted goals, including the preservation of life, even in circumstances in which most would agree that that life is of no benefit to the patient. He addresses the objection that professional integrity overrides this limited obligation and find the objection unconvincing. In short, his aim in this essay is to see the concept of futility finally buried, once and for all. http://imp.oxfordjournals.org/content/early/2015/07/31/imp.jhv019.abstract

End-of-life decisions in pediatric cancer patients

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 July 2015 – This is the first study providing insights into the characteristics of end-of-life decisions (ELDs) from a pediatric oncologist's point of view. In 31 of 48 cases [in a Dutch medical center) one or more ELDs were made. In 20 of 31 cases potentially life-prolonging treatments were discontinued or withheld, and in 22 of 31 cases drugs were administered to alleviate pain or other symptoms in potentially life-shortening dosages. Frequently mentioned considerations for making ELDs were no prospects of improvement and unbearable suffering without a curative perspective. ELDs were discussed with parents in all cases, and with the child in 9 of 31 cases. After the child's death, the pediatric oncologist met the parents in all ELD cases and in 11 of 17 non-ELD cases. Pediatric oncologists were satisfied with care around the child's death in 90% of the ELD cases versus 59% of the non-ELD cases. http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.29000.rbvl

Of related interest:

BMC PALLIATIVE CARE | Online – 4 August 2015 – 'Priorities for global research into children's palliative care: Results of an International Delphi Study.' The top five research priorities identified in this study were: 1) Children's understanding of death and dying; 2) Managing pain in children where there is no morphine; 3) Funding; 4) Training; and, 5) Assessment of the WHO two-step analgesic ladder for pain management in children. Information from this study is important for policy makers, educators, advocates, funding agencies, and governments ... [and] ... provides a much needed starting place for the allocation of funds and building research infrastructure. http://www.biomedcentral.com/content/pdf/s12904-015-0031-1.pdf

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

Nursing home and end-of-life care in Parkinson disease

NEUROLOGY, 2015;85(5):413-419. A large proportion of the Medicare Parkinson disease (PD) population resides in a long term care facility (LTCF). In this nationwide retrospective cohort study, the authors identified 469,055 individuals with PD who received Medicare benefits in 2002. Nearly 25% (more than 100,000 in total) resided in a LTCF. Only 33% of nursing home residents with PD had outpatient neurologist care. LTCF residents who had outpatient neurologist care were twice as likely to utilize hospice services before death. There is substantial unmet need for palliative care in the PD population. Increased efforts to provide specialist care to dependent individuals with PD may improve end-of-life care. http://www.neurology.org/content/85/5/413

Noted in Media Watch, 30 March 2015, #403 (p.11):

CURRENT NEUROLOGY & NEUROSCIENCE REPORTS | Online – 22 March 2015 – 'Palliative care for Parkinson's disease: Has the time come?' Although Parkinson's disease (PD) is traditionally viewed as a movement disorder which affects quality of life, recent literature has revealed an increased mortality, a high burden of difficult-to-manage non-motor symptoms, high caregiver distress, and a high utilization of medical services especially in the last year of life. Current medical systems have yet to adequately respond to this mounting evidence through the adoption of palliative care practices and through the provision of palliative care services to both PD patients and to affected families http://link.springer.com/article/10.1007/s11910-015-0542-4

Noted in Media Watch, 9 June 2014, #361 (p.15):

MEDSCAPE MEDICAL NEWS | Online – 3 June 2014 – 'New European consensus on palliative care in neuro disease.' A new consensus paper for palliative care for patients with progressive neurologic disease emphasizes the special needs of these patients and how neurologists and palliative care specialists can work together to fulfil them. The paper ... is the product of a joint effort of the European Federation of Neurological Societies and the European Association for Palliative Care. <u>http://www.medscape.com/viewarticle/826100</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

JOURNAL OF EVIDENCE BASED MEDICINE & HEALTHCARE, 2015;2(31):4630-4644.
 'Euthanasia – A study of law, policy and ethics [in India].' Physician assisted suicide (PAS) and Euthanasia as it is now known, is essentially the doctrine that when, owing to disease, senility or the like, a person's life has permanently ceased to be either agreeable or useful, the sufferer should be painlessly killed either by himself or by another. The intentional termination of patient's life in such a situation by an act or omission of medical care is called euthanasia or mercy killing. This is the most active area of research in contemporary bio ethics. This article offers a global overview regarding legalization of euthanasia and the current Indian scenario. http://www.jebmh.com/data.pdf/Zachariah%20Thomas.pdf



Barry R. Ashpole

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

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <u>http://hospicecare.com/about-iahpc/newsletter/2015/07/media-watch/</u>

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

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

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

Asia

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

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

Australia

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

Canada

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

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

Europe

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

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

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

Barry R. Ashpole Guelph, Ontario CANADA

[•]phone: 519.837.8936 e-mail: <u>barryashpole@bell.net</u>