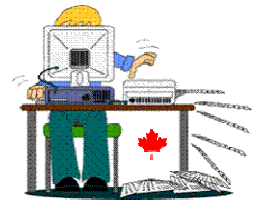


Media Watch...

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.

4 May 2015 Edition | Issue #408



Compilation of Media Watch 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

Towards team-based care and shared responsibility: Scroll down to U.S.A. and 'Doctors and nurses, not learning together' (p.5) in *The New York Times*.

Canada

Canada's Compassionate Care Benefit needs a rethink

THE GLOBE & MAIL | Online OpEd – 29 April 2015 – Under the theme of helping families make ends meet, the 2015 federal budget announced that the Compassionate Care Benefit [CCB] is to be extended ... going from six weeks to six [*sic*] months. The basic aim of this benefit, introduced in 2004, is to better support Canadians caring for a gravely ill family member. Certainly, as a social reform, health care organizations and caregivers welcome this extension to compassionate care benefits and, in a federal election year, it easily seems to be smart politics. With an aging population, we can reasonably assume that claims for compassionate care benefits will continue to increase as working adults respond to the care needs of a gravely ill or dying family member. Employment Insurance (EI) tracking surveys find most working Canadians say they are likely to apply for the CCB in the future if the circumstances arose. But this program is beyond the reach of many Canadians working in non-standard employment. That is, jobs which are part-time, temporary, casual or freelance, seasonal, contract, on-call or contingent. Most non-standard jobs are associated, on average, with lower weekly earnings, lower pension coverage, lower disability and health benefits, little or no job security, and relatively few opportunities for promotions in workplaces. Women are more likely to be in non-standard employment than men. Here is the big public policy question: is the EI system really the best policy platform for this benefit in achieving effective and progressive outcomes for Canadian families? <http://www.theglobeandmail.com/globe-debate/canadas-compassionate-care-benefit-needs-a-rethink/article24164935/>

N.B. According to Statistics Canada in December 2014 1.3 million Canadians over the age of 45 were classified as working part-time; 1.9 million were classified as temporarily employed.

Noted in Media Watch, 27 April 2015, #407 (p.1):

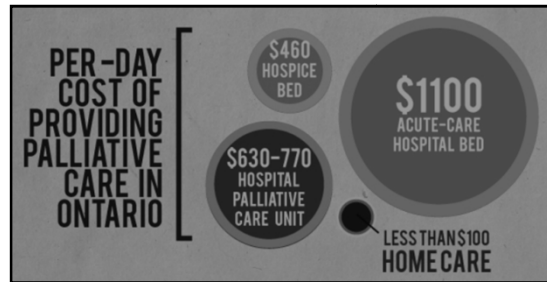
- *THE TORONTO STAR* | Online – 21 April 2015 – '**Federal budget to boost Employment Insurance compassionate care leave.**' The Conservatives will more than double [to 12 weeks] the amount of time Canadians can draw on employment insurance for compassionate leave to care for an ailing loved one... The benefit is meant to assist people forced to take time off work to act as a caregiver to a family member struggling with a grave illness. <http://www.thestar.com/news/canada/2015/04/20/federal-budget-to-boost-ei-compassionate-care-leave.html>

Facing a life-threatening illness or death

We're sick of "broken" health care

ONTARIO | *The London Free Press* – 29 April 2015 – Nearly three-quarters of Canadians don't think they or their loved ones will receive the "comfort and support" they want and expect when facing a life-threatening illness or death, the poll commissioned by think-tank Cardus found.¹ The poll findings show the need for most Canadians to think of an end-of-life plan before they're forced to and when it may be too late, said Ray Pennings, executive vice-president of Cardus.

"Lots of worthwhile things are being done, but we are still in a situation where 75% of Canadians are saying they want to die at home, surrounded by their natural caregiver, and 70% end up dying in hospital," said Pennings. <http://www.lfpress.com/2015/04/28/were-sick-of-broken-health-care>



1. 'Death is natural: Reframing the end-of-life conversation in Canada,' Cardus, Hamilton, Ontario, April 2015. <http://www.cardus.ca/research/health/publications/>

Auditor General takes aim at First Nations health...

CTV NEWS | Online – 28 April 2015 – Canada's auditor general is taking issue with the quality of health care in remote First Nations communities.¹ <http://www.ctvnews.ca/politics/ag-takes-aim-at-first-nations-health-prisoners-and-tax-credit-oversight-1.2348253>

1. 'Access to Health Services for Remote First Nations Communities,' Auditor General of Canada, Spring 2015. http://www.oag-bvg.gc.ca/internet/docs/parl_oag_201504_04_e.pdf

N.B. There is no mention in the Auditor General's report of end-of-life care.

Noted in Media Watch, 2 December 2013, #334 (p.1):

- CTV NEWS | Online – 28 November 2013 – '**Aboriginal seniors face more health challenges, report suggests.**' First Nations, Métis and Inuit of advancing years often have poorer health than their non-aboriginal counterparts, but don't receive the same level of health-care services as other Canadian seniors.¹ Chronic conditions such as obesity, diabetes and heart disease are more prevalent among aboriginal Canadians, compared with the general population, and those disorders can worsen with age. Accessing health care can be physically, emotionally and financially challenging for many aboriginal seniors, who may have to travel to urban centres for services that are unavailable in remote or isolated communities. <http://www.ctvnews.ca/health/aboriginal-seniors-face-more-health-challenges-report-suggests-1.1564234>

1. *Canada's Most Vulnerable: Improving Health Care for First Nations, Métis and Inuit Seniors*, The Health Council of Canada, November 2013. http://healthcouncilcanada.ca/rpt_det_gen.php?id=801&rf=2

Extract from the 2013 Health Council of Canada report

There is no funding for palliative/end-of-life care through the First Nations & Inuit Health Branch, and Health Canada's First Nations and Inuit Home and Community Care program is unable to provide 24-hour support for palliative clients and their families due to limited staffing and funds. Some research with seniors to define culturally appropriate end-of-life care yields a very different perspective from the Western model.

N.B. In this issue of Media Watch is listed selected articles noted in past issues of the weekly report on end-of-life care for Canada's First Nations people.

Courts no place to resolve gut-wrenching medical issues

THE GLOBE & MAIL | Online – 28 April 2015 – The much-publicized case of J.J., a First Nations girl who refused chemotherapy in favour of “traditional medicine,” was resolved amicably. J.J., who is suffering from acute lymphoblastic leukemia, will undergo chemotherapy overseen by an oncologist. The chemo will be complemented by the care of a chief who practises traditional Haudenosaunee medicine: The two will work together as a team rather than at cross-purposes. All the parties involved – the Ontario Court judge, the Attorney-General’s Office, the Brant Family and Children’s Services, McMaster Children’s Hospital, the leaders of the Six Nations of the Grand River, and the lawyers for the family of J.J. – engaged in an orgy of self-congratulation at the outcome. But they should all be ashamed that it took a prolonged dispute, an asinine court ruling that needed to be “amended,” and the suffering of a child before common sense prevailed. The question that begs to be asked is: Why did J.J.’s case end up in the courts in the first place? The law is a blunt instrument and the courts are the worst possible place to try and resolve emotional, heart-wrenching medical issues. <http://www.theglobeandmail.com/globe-debate/courts-no-place-to-resolve-gut-wrenching-medical-issues/article24148846/>

Of related interest:

- *THE GLOBE & MAIL* | Online – 25 April 2015 – ‘**Why traditional healing has a place in modern health care.**’ Traditional healing involves working with a person to help them heal, not just physically but mentally, emotionally and spiritually ... it involves an integrative approach that seeks to balance the body, mind and spirit with the environment. As we learn more about the holistic benefits of traditional medicines and ceremonies, and become more advanced in conventional medicines and practices, we gain a deeper level of respect and understanding for each discipline and acknowledge the importance of recognizing their co-existence in a modern health-care system. <http://www.theglobeandmail.com/life/health-and-fitness/health/why-traditional-healing-has-a-place-in-modern-health-care/article24126195/>

More seniors services needed in British Columbia: Poll

BRITISH COLUMBIA | *The Vancouver Sun* – 26 April 2015 – More than half of British Columbians think the health care system focuses too much on hospitals and emergency rooms and not enough on services like residential care homes, long-term care beds and services for chronically ill seniors, suggests a new poll.¹ The survey ... for the B.C. Care Providers Association showed 62% of residents polled feel the system is too focused on acute care. Daniel Fontaine, of the ... Association, said spending health care dollars to support seniors in residential or home care costs a couple hundred dollars per day, compared to that same senior taking up a bed in an emergency room or hospital for up to \$1,800 a day. The B.C. government is slowly adjusting its policies to reallocate some of the billions of dollars it spends annually on urgent care toward home and community care as it grapples with a growing elderly population, more seniors with complex care needs, clogged emergency rooms and limited money available... <http://www.vancouversun.com/health/seniors/More+seniors+services+needed+poll/11006403/story.html>

Extract from report of the B.C. Care Providers Association poll

Although 85% of British Columbians believe aging is to blame for rising health costs, multiple studies suggest that the impact from aging is modest in comparison to that of other cost drivers, such as inflation and technological innovation. In particular, various studies suggest that growth in healthcare costs due to population aging will be about 1% per year between 2010 and 2036

1. B.C. Care Providers Association Myths & Misconceptions Poll Results: <http://www.bccare.ca/survey/>

Death midwives help families cope with end-of-life care

CBC RADIO | Day 6 (News Magazine) – 26 April 2015 – Death midwifery is a new practice here in Canada. A death midwife (or death doula, as they're sometimes called) can help create death plans, some provide spiritual care, psychological and social support, and sometimes even physical care. They can help plan home vigils and home funerals, and offer guidance with respect to what your rights and responsibilities are in caring for someone who's died. The practice is still evolving. Some death midwives are nurses or grief counselors or chaplains. Some have graduate degrees in divinity studies. Others worked for years in the funeral industry. The practice of death midwifery is unlicensed and unregulated in Canada, but that isn't the case everywhere. In 2009, Oregon ... introduced a bill to regulate the practice of "death care consultants," otherwise known as death doulas and death midwives. The bill was passed in July of that year and someone now wanting to call themselves a death midwife in Oregon is required to obtain a license through the state's Mortuary & Cemetery board." <http://www.cbc.ca/radio/day6/episode-230-omar-khadr-gets-bail-mayweather-vs-pacquiao-death-doulas-and-more-1.3047873/death-midwives-help-families-cope-with-end-of-life-care-1.3047933?cmp=rss>

Noted in Media Watch, 26 January 2015, #394 (p.3):

- U.S. | *The New York Times* – 23 January 2015 – **'Death doulas help the terminally ill, and their families, cope.'** The word doula, Greek for "woman who serves," is usually associated with those who assist in childbirth. But increasingly, doulas are helping people with leaving the world as well. The concept is not completely new; hospices have long had "vigil volunteers" who sit by the bedsides of the dying, but it has now expanded far beyond that. Since there are no federal or state accrediting agencies for death doulas – also called end-of-life doulas, death midwives or simply companions – there are no statistics on how many exist. http://www.nytimes.com/2015/01/24/your-money/death-doulas-help-the-terminally-ill-and-their-families-cope.html?_r=0

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online – 27 April 2015 – **'Doctor-assisted dying law: Promised federal consultation hasn't materialized.'** Two months after Prime Minister Stephen Harper promised to consult widely on doctor-assisted dying, the federal government has yet to reveal how it intends to canvass Canadians' views on the emotional issue – much less how it intends to legislate on the subject. Time is running out. When the Supreme Court struck down the prohibition on physician-assisted dying last February, it gave the federal government 12 months to craft a new law that recognizes the right of clearly consenting adults who are enduring intolerable physical or mental suffering to seek medical help to end their lives. With Parliament scheduled to sit just six more weeks before an extended break for the summer and a fall election, the government has only three or four months in which to introduce, debate and pass a new law. <http://www.cbc.ca/news/politics/doctor-assisted-dying-law-promised-federal-consultation-hasn-t-materialized-1.3049968>
- *THE GLOBE & MAIL* | Online – 27 April 2015 – **'Don't expect law on doctor-assisted suicide before election, MacKay says.'** The federal government will not introduce new legislation to govern doctor-assisted dying before the expected October federal election, Justice Minister Peter MacKay said Monday. Rather, said Mr. MacKay, the government will soon reveal details of its long-promised public consultations on the emotionally charged issue, noting that Justice Department officials are working behind the scenes to frame the discussion. <http://www.theglobeandmail.com/news/national/dont-expect-law-on-doctor-assisted-suicide-before-election-mackay-says/article24147566/>

N.B. Noted in Media Watch, 27 April 2015, #407 (p.3): A federal government commission will embark on a six-month tour to probe Canadians' views on assisted dying, according to *Le Devoir*: 'Une commission itinérante sur l'aide médicale à mourir, tranche le gouvernement fédéral.' <http://www.ledevoir.com/politique/canada/437906/une-commission-itinerante-sur-l-aide-medicale-a-mourir-tranche-le-gouvernement-federal>

U.S.A.

Medicare to pay hospices \$200 million more in fiscal 2016

MODERN HEALTHCARE | Online – 30 April 2015 – The Centers for Medicare & Medicaid Services is proposing hospices get a 1.3% rate increase from Medicare under... The proposed payment rule means Medicare would spend \$200 million more on hospices in fiscal 2016 than in fiscal 2015. There are more than 4,000 hospices nationwide. The number of Medicare beneficiaries receiving hospice services grew from 513,000 in fiscal 2000 to more than 1.3 million in fiscal 2013. Medicare hospice expenditures grew from \$2.8 billion to an esti-

mated \$15.3 billion during that period. The disproportionate increase in spending is partly because of an 82% increase in the average length of stay for beneficiaries... <http://www.modernhealthcare.com/article/20150430/NEWS/150439987>

Specialist Publications

'Is care for the dying improving in the U.S.?'
(p.12), in *Journal of Palliative Medicine*.

Doctors and nurses, not learning together

THE NEW YORK TIMES | Online – 30 April 2015 – There is surprisingly little education on what it means to be a leader of a medical team, with its nurses, physician assistants, pharmacists, respiratory therapists, physical therapists, dieticians and case managers. There is even less discussion of how to understand one another's roles, perspectives, frustrations and limitations. Instead, traditional education emphasizes separate training for each health professional, which inadequately prepares students and residents for new models of health care delivery that emphasize team-based care and shared responsibility for patients. The push toward more collaborative care has been underway for years. In 2001, the Institute of Medicine issued a report recommending that all health professionals receive training in interdisciplinary teams.¹ Since then, the Accreditation Council for Graduate Medical Education has integrated interprofessional learning into its competency milestones.² A central goal of health care overhaul – beyond improving access to care – is transforming a fragmented health system into a more unified one through better team-based care models. http://well.blogs.nytimes.com/2015/04/30/doctors-and-nurses-not-learning-together/?ref=health&_r=0

Admitted to your bedroom: Some hospitals try treating patients at home

THE NEW YORK TIMES | Online – 27 April 2015 – Under pressure to reduce costs while improving quality, a handful of hospital systems have embarked on an unusual experiment: They are taking the house call to the extreme, offering hospital-level treatment at home to patients ... who in the past would have been routinely placed in a hospital room. And as awareness spreads of the dangers that hospitalization may pose, particularly to older adults, patients are enthusiastically seizing the opportunity. http://well.blogs.nytimes.com/2015/04/27/admitted-to-your-bedroom-some-hospitals-try-treating-patients-at-home/?ref=health&_r=0

Of related interest:

- *THE NEW YORK TIMES* | Online – 24 April 2015 – **'Nursing homes are starting to supplant hospitals as focus of basic health care.'** The notion that a hospital remains the safest place for old patients dies hard. Many families still believe their aging relatives belong in a hospital when they're ailing. But 20-plus years of research have documented the risks of hospitalization for older adults, particularly those frail or ill enough to need nursing home care. <http://www.nytimes.com/2015/04/28/science/nursing-homes-are-starting-to-supplant-hospitals-as-focus-of-basic-health-care.html?ref=health>

International

End-of-life care in Australia

Emerald's Fernlea House forced to cut palliative care for patients under 65

AUSTRALIA (Victoria) | *The Free Press Leader* (Emerald) – 28 April 2015 – Emerald's Fernlea House could be facing a dire financial battle to care for the terminally ill under the age of 65, thanks to a new government funding system which kicks in from 1 July. Half its patients are under the age of 65. The new system, which will see these younger patients out in the cold, is the combination of the Federal Government's Commonwealth Home & Community Program, the National Respite for Carers Program, and the Day Therapy Centres Program into a single streamlined Commonwealth Home Support Programme. <http://www.heraldsun.com.au/leader/outer-east/emeralds-fernlea-house-forced-to-cut-palliative-care-for-patients-under-65/story-fnrwkhlp-1227323159706>

End-of-life in China

Attitudes toward death exposed in survey

CHINA | *The Standard* (Hong Kong) – 28 April 2015 – The University of Hong Kong Centre on Behavioral Health interviewed 1,123 people between June and December [2014] on attitudes toward death, advance directives and end-of-life care preferences, organ and body donations, and funeral/burial arrangements. It found 32% of respondents agreeing people should adhere to the belief one should stay away from social occasions soon after a death in the family. That is higher than for other beliefs: 14% for "seeing a dead body or a coffin can bring bad luck," 16% for "a parent should not attend the funeral of one's child" and 12% for "talking about death in front of a dying person could accelerate death." About 74% support the use of advance directives written statements of a person's wishes regarding treatment to ensure those wishes are carried out should the person be unable to communicate; 31% have not heard of advance directives. Fifty percent prefer to be at home to receive end-of-life care, while 23% would rather be in hospital. http://www.thestandard.com.hk/news_detail.asp?we_cat=4&art_id=156511&sid=44349233&contype=1&d_str=20150428&fc=1

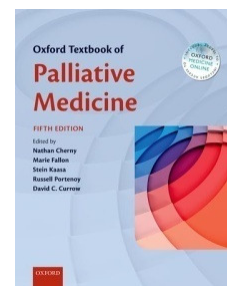


Barry R. Ashpole

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>

Communication with the Public, Politicians, and the News Media

by Barry R. Ashpole



See Section 6.4 (pp.357-359) of the 5th edition of the *Oxford Textbook of Palliative Medicine*: <http://fdslive.oup.com/www.oup.com/academic/pdf/13/9780199656097.pdf>

End-of-life care in England

Charities say letting people die at home could save millions for National Health Service

U.K. | *The Guardian* – 27 April 2015 – The National Health Service could save millions of pounds if the majority of people who died of a terminal illness in hospital did so at home as most wished to do, charities have said. Figures from the latest Office for National Statistics survey of bereaved people found 85% of those who died in hospital in 2013 had expressed a desire to die at home. Marie Curie, which provides care and support to people with terminal illness, said patients were being denied the choice because of factors including a lack of 24/7 community support, poor coordination between services, and the failure to provide fast and free social care support for people at the end of life. The charity said there was scope for

savings to be made by helping those who wanted to spend their final days at home to do so. With access to high-quality nursing care in the community, total care costs could be as much as £500 lower per person.¹ <http://www.theguardian.com/lifeandstyle/2015/apr/27/die-at-home-save-millions-nhs-palliative-care>

Specialist Publications

'Enabling a family caregiver-led assessment of support needs in home-based palliative care: Potential translation into practice' (p.14), in *Palliative Medicine*.

1. 'Exploring the cost of care at the end of life,' The Nuffield Trust, September 2014. The authors state that assessing costs associated with institutional hospice care was difficult. Their best estimates were that costs were of the order of £400 per day, so that an average 14-day stay amounted to £5,600. Averaged over all people who died they estimated a total inpatient hospice cost of approximately £550 per person. [Noted in Media Watch, 29 September 2014, #377 (p.5)] http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end_of_life_care.pdf

Over 75? Sign here if you're ready for death: GPs to ask ALL older patients if they'll agree to a "do not resuscitate" order

U.K. (England) | *The Daily Mail* – 26 April 2015 – New National Health Service (NHS) guidelines urge GPs to draw up end-of-life plans for over-75s, as well as younger patients suffering from cancer, dementia, heart disease or serious lung conditions. They are also being told to ask whether the patient wants doctors to try to resuscitate them if their health suddenly deteriorates. The NHS says the guidance will improve patients' end-of-life care, but medical professionals say it is "blatantly wrong" and will frighten the elderly into thinking they are being "written off." In some surgeries, nurses are cold-calling patients over 75 or with long-term conditions and asking them over the phone if they have "thought about resuscitation." Other patients have spoken of the shock of going in for a routine check-up and being asked about resuscitation. The extraordinary guidance has been brought in despite the outcry over the use of "do not resuscitate" orders under the Liverpool Care Pathway. The discredited

pathway was scrapped last year after the *Mail* revealed that doctors were placing DNR notices on patients without their knowledge and depriving them of food and fluids. <http://www.dailymail.co.uk/news/article-3056621/Over-75-Sign-ready-death-GPs-ask-older-patients-ll-agree-not-resuscitate-order.html>

Life expectancy in England & Wales

National life expectancy in 2030 is expected to reach 85.7 years for men and 87.6 years for women, further reducing the female advantage to 1.9 years.

Source: 'The future of life expectancy and life expectancy inequalities in England and Wales: Bayesian spatiotemporal forecasting,' *The Lancet*, 29 April 2015. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)60296-3/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)60296-3/abstract)

Cont.

Noted in Media Watch, 27 October 2014, #381 (p.6):

- U.K. (England) | BBC News – 20 October 2014 – **‘Do not resuscitate patient controversy.’** A recent landmark judgement regarding do not resuscitate orders by the Court of Appeal is starting to have profound effects on patient care.¹ Under the ruling doctors must ask patients – and/or their relatives – whether they want to be resuscitated in the event, for example, of a cardiac or respiratory arrest. <http://www.bbc.com/news/uk-england-29631353>

1. ‘Legal duty over resuscitation orders,’ BBC News, 17 June 2014. [Noted in Media Watch, 23 June 2014, #363 (p.6)] <http://www.bbc.com/news/health-27886265>

Noted in Media Watch, 13 October 2014, #379 (p.11):

- U.K. | British Medical Association, Resuscitation Council and the Royal College of Nursing – Accessed 8 October 2014 – **‘Decisions relating to cardiopulmonary resuscitation.’** This new [3rd] edition identifies key ethical and legal principles that should inform all CPR decisions. <https://www.resus.org.uk/pages/DecisionsRelatingToCPR.pdf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SOUTH AFRICA | BBC News – 30 April 2015 – **‘South African court grants man “right to die.”’** [In a landmark ruling] the Pretoria High Court ruled that Robin Stransham-Ford, 65, who was diagnosed with terminal prostate cancer in 2013, could allow a doctor to help him end his life. Judge Hans Fabricius said that the doctor treating him could not now be prosecuted or face disciplinary action. <http://m.bbc.com/news/world-africa-32530580>
- U.K. (England & Wales) | BBC News – 28 April 2015 – **‘Assisted suicide review granted by High Court judges.’** Disability rights campaigners who say assisted suicide policy in England & Wales is too “liberal” have won permission to bring a legal challenge. Director of public prosecutions Alison Saunders last year clarified assisted suicide guidelines, making prosecutions of health professionals less likely. <http://www.bbc.com/news/uk-32502800>

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.

Back Issues of Media Watch

The screenshot shows the IPCRC.NET website. The header includes the logo 'IPCRC.NET International Palliative Care Resource Center' and a navigation menu with links: Home, About IPM, CIA, NCI, Partners, Contact, and Acknowledgements. Below the header, there is a section for 'GLOBAL PALLIATIVE CARE NEWS ARCHIVE' and 'MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE'. A sidebar on the right titled 'Media Watch Archives' lists the following categories: 2014, July - December; 2014, January - June; 2013, July - December; 2013, January - June; 2012, July - December; 2012, January - June; 2011, July - December; 2011, January - June; and Current. The main content area shows a snippet of a news article titled 'MW 400: Palliative care in advanced lung disease: The challenge of integrating palliation into everyday care' with a download link for the complete issue (PDF 450 KB).

<http://www.ipcrc.net/archive-global-palliative-care-news.php>

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

Palliative care in South Asia: A systematic review of the evidence for care models, interventions, and outcomes

BMC RESEARCH NOTES | Online 30 April 2015 –

The increasing incidence of cancer and chronic diseases in South Asia has created a growing public health and clinical need for palliative care in the region. As an emerging discipline with increasing coverage, palliative care must be guided by evidence. In order to appraise the state of the science and inform policy and best practice in South Asia this study aimed to systematically review the evidence for palliative care models, interventions, and outcomes. The search identified only 16 articles, reporting a small range of services. The 16 articles identified India as having greatest number of papers within South Asia, largely focused in the state of Kerala. Nepal and Pakistan reported a single study each, with nothing



from Bhutan, Afghanistan, Maldives or Bangladesh. Despite the large population of South Asia, the authors found only 4 studies reporting intervention outcomes, with the remaining reporting service descriptions. The dearth of evidence in terms of palliative care outcomes, and the lack of data from beyond India, highlight the urgent need for greater research investment and activity to guide the development of feasible, acceptable, appropriate and effective palliative care services. There is some evidence that suggests implementation of successful and well-developed community based models of palliative care may be replicated in other resource limited settings. <http://www.biomedcentral.com/content/pdf/s13104-015-1102-3.pdf>

N.B. South Asia accounts for approximately one-fifth of the world's population, i.e., 1.7 billion.

Are we preparing GP trainees for patient death?

BRITISH JOURNAL OF GENERAL PRACTICE | Online – 1 May 2015 – Patient death is identified as the greatest stressor in medical practice and it can significantly reduce a doctor's wellbeing, inducing a moderate-to-strong emotional effect in nearly two-thirds of hospital doctors. GPs report experiencing such emotions as sadness, guilt, stress, frustration, and anger... Is there any place for death in the young doctor's idealistic world? A study showed that less than 25% of foundation year 1 doctors are aware that, after qualifying, they will be responsible for a dying patient and experience patient death in the course of their duties. Young doctors facing the death of a patient for the first time experience a similar range of negative feelings as senior doctors, such as sadness, guilt, disgust, and confusion, with a sense of self-blame because of a perceived professional failure to save lives. Trainees are not always effectively taught how to speak about a patient's death. Even more experienced doctors express the belief that showing negative feelings associated with patients is a sign of weakness. They are afraid to be perceived by their peers and supervisors as being too sensitive for this profession. <http://bjgp.org/content/65/634/248>

Spirituality in geriatric palliative care

CLINICS IN GERIATRIC MEDICINE, 2015;31(2):245-252. This article presents an overview of spirituality as an essential domain of geriatrics palliative care, and provides guidelines for clinicians to diagnose spiritual distress and to integrate spirituality into their clinical practice. [http://www.geriatric.theclinics.com/article/S0749-0690\(15\)00012-9/abstract](http://www.geriatric.theclinics.com/article/S0749-0690(15)00012-9/abstract)

Expressions of loss and separation

Automatic and automated mourning: Messengers of death and messages from the dead

CONTINUUM: JOURNAL OF MEDIA & CULTURAL STUDIES | Online – 24 April 2015 – Recognizing that someone has died and ritualizing this loss requires forms of communication and mediation between individuals and families in relation to wider social networks. Media has always played a significant part in how people are informed of a death, enabling rituals to proceed such as death notices and obituaries in newspapers. Today, information communication technologies (ICTs) and social media are routinely part of how people are informed about death, and enact a range of socially shared mourning and remembrance processes. This paper explores the current deployment of ICTs and social networking within practices and rituals of mourning, applying media theory. It focuses on the temporality of mourning in a culture of speed and the activation of mourning from the announcement of death to the cycles of anniversaries via social networking culture and through technological forms of automation. <http://www.tandfonline.com/doi/abs/10.1080/10304312.2015.1025369#>

An investigation into how tombstones and epitaphs in the cemetery at Albury, New South Wales, reflect grief and memorial trends

HISTORY IN THE MAKING, 2015;4(1):27-43. The Victorian “cult of mourning” ... emphasised public displays of grief. The dual processes of secularisation and World War I brought an end to public grief. Following World War II, death became taboo in Western society as medicine and bureaucracy moved death out of its traditional place in the home and into cemeteries styled as landscaped gardens. The work of psychiatrists in promoting the acceptance of grief in the late twentieth-century has allowed the public celebration and memorialisation of the dead to become culturally appropriate again. Rather than grand Victorian funerals, however, this memorialisation takes the form of more individual and customised gravestones, “In Memoriam” notices in newspapers, and, in the case of those cremated whose remains are scattered rather than interred, no permanent memorial at all. <https://historyitm.files.wordpress.com/2015/04/morgan.pdf>

Implantable cardioverter defibrillator (ICD) deactivation discussions: Reality versus recommendations

EUROPEAN JOURNAL OF CARDIOVASCULAR NURSING | Online – 22 April 2015 – As rates of device implantation continue to rise throughout Europe, European and international guidelines recommend professionals discuss deactivation with patients. In reality the appropriate therapeutic management of an ICD at the end-of-life remains uncertain in the minds of professionals and patients. There was no documented evidence [in this study that] patients were informed about deactivation prior to ICD implantation. End-of-life management was discussed with twenty three patients and on seventeen occasions deactivation was included. Patients were not adequately informed regarding device deactivation prior to implantation, nor when their health deteriorated. <http://cnu.sagepub.com/content/early/2015/04/22/1474515115584248.abstract>

Noted in Media Watch, 23 March 2015, #402 (p.11):

- RESUSCITATION COUNCIL (U.K.), BRITISH CARDIOVASCULAR SOCIETY & NATIONAL COUNCIL FOR PALLIATIVE CARE | Online – March 2015 – ‘**Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death.**’ Challenges arise when people with an implanted device approach or reach the end of their life. Receiving treatment (i.e., electric shocks from an ICD) as they are dying may provide no benefit but may cause them pain and may cause distress both to them and to those who care about them. https://www.resus.org.uk/pages/CIEDs_Guidance.pdf

Cont.

Noted in Media Watch, 23 February 2015, #398 (p.14):

- *PACING & CLINICAL ELECTROPHYSIOLOGY* | Online – 14 February 2015 – '**Defibrillator deactivation against a patient's wishes: Perspectives of electrophysiology practitioners.**' Survey respondents were from Europe, Asia, Australia, South American and Africa. The majority were from North American (78%), were academically affiliated (64%), and practiced in an urban setting (67.8%). The majority responded that it was not ethical/moral for doctors to deactivate ICDs against patients' wishes or against family/surrogates' wishes, even in the context of medical futility. <http://onlinelibrary.wiley.com/doi/10.1111/pace.12614/abstract>

N.B. See Media Watch dated 12 January 2015, #392 (p.9) for a listing of selected articles on defibrillator deactivation in the context of end-of-life care noted in past issues of the weekly report.

Transitions between health care settings in the final three months of life in four European Union (EU) countries

EUROPEAN JOURNAL OF PUBLIC HEALTH | Online – 31 March 2015 – Transitions between care settings may be related to poor quality in end-of-life care. Yet there is a lack of cross-national population-based data on transitions at the end of life. Among 4,791 non-sudden deaths in Belgium, Netherlands, Italy and Spain, 59%, 55%, 60% and 58%, respectively, were transferred between care settings at least once in the final 3 months of life (10%, 8%, 10% and 13% in final 3 days of life); 10%, 5%, 8% and 12% were transferred three times or more. In all countries, transitions were more frequent among patients residing at home (61-73%) than among patients residing in a care home (33-40%). Three months before death 5-7% of patients were in hospital, and this rose to 27-39% on the day of death. Patient wishes were cited as the reason for the last transition before death in 27%, 39%, 9% and 6% of cases in Belgium, Netherlands, Italy and Spain, respectively. <http://eurpub.oxfordjournals.org/content/early/2015/03/30/eurpub.ckv039>

End-of-life care in Italy

Mutual needs and wishes of cancer patients and their family caregivers during the last week of life: A descriptive phenomenological study

JOURNAL OF HOLISTIC NURSING | Online – 24 April 2015 – Needs and wishes in the last week of life were focused on four main themes: 1) remaining attached to my life (“I wish I was doing things like I used to”); 2) detaching myself from life, immediately (“I wish this Calvary were over”); 3) dealing with the dying process (“waiting in fear”); and, 4) starting to think of life without each other (“unshared worries”). In order to improve personalized care in the last week of life, nurses are encouraged to assess patient and caregiver needs and wishes, as well as their reciprocal influence and correspondence, to identify each patient-caregiver unit's unique holistic care priorities. <http://jhn.sagepub.com/content/early/2015/04/22/0898010115581936.abstract>

First facilities for palliative paediatric care in Italy: project for the G. Gaslini Institute in Genoa

JOURNAL OF TECHNOLOGY FOR ARCHITECTURE & ENVIRONMENT, 2015;9:199-207. The quality of the Italian National Health Scheme is measured according to the efficiency of community services and their capacity of complying with the new emerging needs of citizens. Among these, hospices can be considered necessary facilities of reference in the case of “palliative care.” Many are reserved for adults, whereas only one facility (located in Padua) complies with the specific and diverse needs of children. <http://www.fupress.net/index.php/techne/article/view/16122>

N.B. Bilingual (Italian and English) language article with a link to full text.

Cont.

Of related interest:

- *JOURNAL OF MEDICAL ETHICS* | Online – 29 April 2015 – **‘Re-engineering shared decision-making.’** A re-engineered model is proposed in which physicians elicit and prioritise patients’ goals of care and then help translate those goals into treatment options, after clarifying the patient’s underlying health status. Preliminary evidence suggests that each step of this revised process is feasible and that patients and physicians are comfortable with this strategy. <http://jme.bmj.com/content/early/2015/04/29/medethics-2014-102618.abstract>
- *JOURNAL OF TRANSCULTURAL NURSING* | Online – 22 April 2015 – **‘Nursing roles and strategies in end-of-life decision making concerning elderly immigrants admitted to acute care hospitals: An Australian study.’** Despite feeling underprepared for their role, participants fostered culturally meaningful care by “doing the ground work,” “facilitating families,” “fostering trust,” and “allaying fear.” The Australian nursing profession has a significant role to play in leading policy, education, practice, and consumer engagement initiatives aimed at ensuring a culturally responsive approach to end-of-life care for Australia’s aging immigrant population. <http://tcn.sagepub.com/content/early/2015/04/21/1043659615582088.abstract>

Is care for the dying improving in the U.S.?

JOURNAL OF PALLIATIVE MEDICINE | Online – 29 April 2015 – Striking changes occurred in health care in the U.S. between 2000 and 2013, including growth of hospice and hospital-based palliative care teams, and changes in Medicare payment policies. The aim of this study was to compare informants’ reports and ratings of the quality of end-of-life care for decedents between 2000 and 2011–2013. A total of 1,208 informants were interviewed; 622 in 2000 and 586 in 2011–2013. Respondents from deaths in 2011–2013 were more likely to state that their loved ones experienced an unmet need for pain management (25.2% versus 15.5% in 2000...). More respondents reported that religion and spirituality were addressed in the later time period (72.4% not addressed compared with 58.3%...). High rates of unmet need for palliation of dyspnea and anxiety/depression remained. The overall rating of quality did not improve but decreased (with 56.7% stating care was excellent in 2000 and 47.0% in the later survey...). Substantial unmet needs in end-of-life care remain. Continued efforts are needed to improve the quality of end-of-life care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0039>

Care after death

‘Bathing & Honoring’ nursing intervention benefits families after patients die in acute care setting

ONCOLOGY NURSE ADVISOR | Online – 25 April 2015 – ‘Bathing & Honoring’ a patient who has died “provides a final positive experience for family members and allows them to begin the grieving process,” according to a report on the practice presented at the [recent] Oncology Nursing Society (ONS) Congress.¹ “Approximately one-third of the U.S. population dies in acute care hospitals,” said Debra Rodgers RN ... of Santa Barbara Cottage Hospital in Santa Barbara, California. “Although nurses are expected to give compassionate care around the time of death, the literature lacks specific evidenced-based interventions for care after death.” The hospital conducted a qualitative study to examine the experiences of family members, all of whom were offered the opportunity to participate in bathing their loved one and reciting non-denominational honoring words following his or her death... <http://www.oncologynurseadvisor.com/bathing-and-honoring-nursing-intervention-benefits-families-after-patients-die-in-acute-care-setting/article/411177/>

1. ‘Beyond the final breath: Nursing care at the time of death’ (abstract), April 2015. http://aahpm.org/uploads/microsites/Abstracts_2015/Beyond_the_Final_Breath_Nursing_Care_at_the_Time_of_Death_FR457C.pdf

Cont.

Noted in Media Watch, 27 April 2015, #407 (p.7):

- U.K. (England & Wales) | National End-of-Life Care Programme & National Nurse Consultant Group – 22 April 2015 – ‘**Updated guidance for professionals who provide care after death.**’ The nurses’ role at the end of life extends beyond death to provide care for the deceased person and support to their family and carers. The physical care given by nurses following death in hospitals has traditionally been referred to as “last offices.” However, in this guidance the authors refer to “care after death,” a term more befitting of our multi-cultural society. http://www.nhsig.nhs.uk/media/2426968/care_after_death_guidance.pdf

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/04/media-watch/#lived>

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

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

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

Asia

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

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

Australia

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

Canada

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

ONTARIO | 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>

Quotable Quotes

People do not care about how much you know unless they know how much you care.
Theodore Roosevelt (1858-1919)

Enabling a family caregiver-led assessment of support needs in home-based palliative care: Potential translation into practice

PALLIATIVE MEDICINE | Online – 28 April 2015 – This review adds to what has been known for over two decades in relation to patient and family priorities for end-of-life care within the hospital setting. The challenge for health care services is to act on this evidence, reconfigure care systems accordingly, and ensure universal access to optimal end-of-life care within hospitals. Of 1,859 articles, 8 met the inclusion criteria generating data from 1,141 patients and 3,117 families. Synthesis of the top five elements identified four common end-of-life care domains considered important to both patients and their families, namely: 1) effective communication and shared decision making; 2) expert care; 3) respectful and compassionate care; and, 4) trust and confidence in clinicians. The final domains differed with financial affairs being important to families, while an adequate environment for care and minimising burden both being important to patients. <http://pmj.sagepub.com/content/early/2015/04/17/0269216315583436.abstract>

Of related interest:

- *BMC PALLIATIVE CARE* | Online – 3 May 2015 – ‘**Development of the Carers’ Alert Thermometer (CAT) to identify family carers struggling with caring for someone dying at home: A mixed method consensus study.**’ The CAT enables the identification of current needs and potential future needs so a proactive approach can be taken to support the carer as their role develops over time, ultimately enabling them to maintain their well-being and to provide end-of-life care at home. Although developed in the U.K., the CAT has the potential to be adopted internationally and across a range of other long term conditions and settings. <http://www.biomedcentral.com/content/pdf/s12904-015-0010-6.pdf>

[Media Watch: Editorial Practice](#)

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

[Distribution](#)

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

[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.

Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review

PALLIATIVE MEDICINE | Online – 28 April 2015 – Despite standardization in disease assessments and curative interventions for childhood cancer, palliative assessments and psychosocial interventions remain diverse and disparate. Integration of patient, parent, and clinician perspectives on end-of-life needs as gathered from primary manuscripts ... revealed mutual themes across stakeholders: holding to hope, communicating honestly, striving for relief from symptom burden, and caring for one another. Integration of themes from primary author palliative care outcome reports ... revealed the following shared priorities in cancer settings: care access; cost analysis; social support to include primary caregiver support, sibling care, bereavement outreach; symptom assessment and interventions to include both physical and psychological symptoms; communication approaches to include decision-making; and overall care quality. <http://pmj.sagepub.com/content/early/2015/04/22/0269216315583446.abstract>

[Media Watch Online](#)

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/04/media-watch/#lived>

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

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

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

Asia

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

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

Australia

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

Canada

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

ONTARIO | 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>

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net