Media Watch...

is intended as an advocacy and research tool. The weekly report is international in scope and distribution — to colleagues who are active or have a special interest in hospice and palliative care, and in the quality of end-of-life care in general — to help keep them abreast of current, emerging and related issues — and, to inform discussion and encourage further inquiry.

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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

Compiled & Annotated by Barry R. Ashpole

When an employee suffers a bereavement: Scroll down to <u>Specialist Publications</u> and 'Building a compassionate community: Developing an informed and caring workplace in response to employee bereavement' (p.8), in *Bereavement Care*.

Canada

Alberta Health Services reverses cuts to home, palliative and continuing care

ALBERTA | The Canadian Press – 18 June 2013 – Alberta Health Services [AHS] is reversing several decisions affecting palliative, home care and continuing care. It won't cancel home care contracts with three Edmonton-based supportive living co-operatives. AHS says that's because it recognizes the unique, specialized care they provide. As well, the "first available bed" policy which required continuing care residents to accept a placement within 100 kilometres of their home has also been withdrawn, effective immediately. AHS has also reached an agreement with 13 home care providers to provide care and support to Calgary and Edmonton clients as home care services expand. The changes come almost a week after Health Minister Fred Horne fired the entire AHS board over its refusal to cancel \$3.2 million in bonuses for health executives and appointed Janet Davidson as an administrator. http://www.globalpost.com/dispatch/news/the-canadian-press/130618/alberta-health-services-reverses-cuts-home-palliative-and-co

N.B. Noted in Media Watch, 3 June 2013, #308 (p.2), are reports on the impact of what was originally proposed by AHS with regard home and palliative care.



12 October 2013

http://www.worldday.org/

Media Watch Online

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care community-at-large. See a complete listing on p.14.

U.S.A.

Cost of Dying: A shift in how we end our lives

CALIFORNIA | San Jose Mercury-News -22 June 2013 - The experience of death is changing in America, gradually shifting from costly, high-tech battles against death in hospitals into hospices that gently accept the inevitable end. A new national database shows that 25% of Medicare patients died in a hospital in 2010, down from 28% in 2007. More than 47% died in hospice environments, often at home, up from 42%. The Bay Area mirrors the trend, but hospital deaths still exceed the national average: Medicare patients' death rates in Bay Area hospitals range from about 30% in the Contra Costa, Alameda and San Mateo regions to 33% in San Francisco's, a modest decline since 2007. Hospital deaths declined precipitously in Santa Cruz, from 30% in 2007 to 20% in 2010. Only the San Jose region saw an increase, rising to 33% from 30.5% four years earlier. This newspaper's [awarding winning] series 'The Cost of Dying' last year outlined a growing interest in alleviating unnecessary suffering and expensive interventions at the end of life by shifting patients to hospice and family homes where caregivers try to ease the discomforts of dying. http://www.mercurynews.com/cost-ofdying/ci 23516746/cost-dying-shift-how-weend-our-lives

1. Tracking Improvement in the Care of Chronically III Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life, June 2013. [Noted in Media Watch, 17 June 2013, #310 http://www.dartmouthatlas.org/down loads/reports/EOL brief 061213.pd

N.B. The San Jose Mercury-News 'Cost of Dying' series has been noted in Media Watch, most recently in the 24 March 2013 issue (p.3). The newspaper's series website: www.mercurynews.com/cost-of-dying

End-of-life care and cost: **Dartmouth Atlas' puzzling findings**

VERMONT (White River Junction) | Valley News (OpEd) – 16 June 2013 – A new report analyzing Medicare data shows that patients are increasingly choosing hospice care over hospitalization at the end of their lives. The study, done by the Dartmouth Atlas Project, reported an 11% decrease in hospital deaths from 2007 to 2010, with the number of days patients spent in the hospital in the last six months of life falling 9.5%, to just less than 10 days on average. The portion of patients choosing hospice rose from 42% to 48% over that three-year period. The results were not consistent across all hospitals or regions of the nation, of course. By our way of thinking, this constitutes progress, in the sense that a good death is one consistent with the values of the life it brings to an end. But, of course, while the quality of a patient's final days is paramount, it is not the only consideration for a bloated health care system like America's. The theory has long been that since so much spending occurs in the context of aggressive medical treatment at the end of life, reducing the hospital stays of dying patients would lead to lower costs. That makes sense, but what's puzzling about the Dartmouth Atlas report is that despite more use of hospice and less dependence on hospitalization at the end of life, "Medicare spending per patient during the last two years of life rose from \$60,694 to \$69,947, a 15.2% increase during a period when the consumer price index rose only 5.3%." The explanation offered by David Goodman, one of the study's principal investigators, is that the fee-forservice model is to blame, because doctors are paid according to the volume of care they provide, encouraging them to provide more services. The assumption is that once the health care system shifts toward rewarding providers for keeping people healthy rather than treating them when they are sick, the cost issue will be contained. http://www.vnews.com/home/7036218-95/editorial-end-of-life-care-and-cost-dartmouth-

atlas-puzzling-findings

Demographics, family caregiving demands call for modernizing workplace leave for caregivers

AMERICAN ASSOCIATION FOR RETIRED PERSONS | Online – 17 June 2013 – A new report argues for improving family leave for working caregivers, citing the growing population of older Americans, increasing numbers of family caregivers on the job, and escalating demands and stress on caregivers.1 The report points to three policy solutions to ease the burden on both caregivers and employers: unpaid family and medical leave, paid family and medical leave insurance, and earned sick time. Close to three out of four women of prime caregiving age are in the workforce and 74% of adults with eldercare responsibilities have been in the workforce at some point in their caregiving. One in four retirees report leaving the workforce earlier than planned to care for an ill spouse or other family member. One in five workers age 45 to 74 expects to take time off for caregiving in the next five years. http://www.aarp.org/about-aarp/press-center/info-06-2013/Demographics-Family-Caregiving-Demands-Call-For-Modernizing-Leave-for-Caregivers-Says-New-AARP-Report.html

Specialist Publications

'Building a compassionate community: Developing an informed and caring workplace in response to employee bereavement' (p.8), in Bereavement Care.

'Towards better support for family carers: A richer understanding' (p.13), in *Palliative Medicine*.

 Keeping Up with the Times: Supporting Family Caregivers with Workplace Leave Policies, American Association for Retired Persons, Public Policy Institute, Washington, June 2013. http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/fmla-insight-keeping-up-with-time-AARP-ppi-ltc.pdf

Noted in Media Watch, 1 October 2012, #273 (p.2):

- WASHINGTON DC | The Washington Post 24 September 2012 'Family leave: Not a benefit, a protection.' A radical, if little noticed, idea came out of the Center for American Progress.¹ Staff there ran the numbers and found a feasible, relatively painless way to offer U.S. workers paid family leave ... one of those issues that at the moment has plenty of supporters but no political weight. http://www.washingtonpost.com/blogs/on-parenting/post/family-leave-not-a-benefit-a-protection/2012/09/21/124961b6-041d-11e2-91e7-2962c74e7738 blog.html
 - Comprehensive Paid Family and Medical Leave for Today's Families and Workplaces: Crafting a System that Builds on the Experience of Existing Federal and State Programs, Center for American Progress, August 2012. http://www.americanprogress.org/wp-content/uploads/2012/09/BousheyUniversalFamilyLeavePaper.pdf

Of related interest:

- USA TODAY | Online 20 June 2013 'Family caregivers on the rise, study says.' More family caregivers are at the front lines of health care than ever before, and they're turning to the Internet to help ease their burden, a new study says. The study shows the portion of adults who are family caregivers jumped from 30% in 2010 to 39% in 2012. Almost two-thirds support a parent or in-law. http://www.usatoday.com/story/news/nation/2013/06/20/number-of-family-care-givers-increases-according-to-study/2438827/
 - Family Caregivers are Wired for Health, Pew Research Center, Washington, 20 June 2013. http://www.pewinternet.org/Reports/2013/Family-Caregivers/Summary-of-Findings.aspx

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON STATE | The Associated Press 20 June 2013 'Washington assisted suicide report shows 17% jump in people requesting lethal prescriptions.' Washington State's annual assisted suicide report shows a 17% jump in the number of people requesting lethal prescriptions in 2012 when compared to the previous year. At least 83 people died after taking medication. According to the report, 376 terminally adults have received the lethal prescription since the law passed in 2009. In 2012, 121 people requested and received the medication. The report shows participants who died in 2012 were between the ages of 35 and 95. http://www.oregonlive.com/pacific-northwest-news/index.ssf/2013/06/washington assisted suicide re.html
 - Death with Dignity Act , Washington State Department of Health, website: http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct.aspx

International

End-of-life care in Singapore

More patients living out final days at home

SINGAPORE | *The Sunday Times* – 23 June 2013 – Many more people are living out their final days in the comfort of home, according to Ministry of Health figures. Currently, about 5,000 people are being cared for in their own homes. In contrast, 1,700 people were able to have this care for the whole of 2009. The numbers are set to rise as more become aware of the benefits of end-of-life care, along with efforts by the Government and care providers to increase accessibility to such services. http://www.straitstimes.com/breaking-news/singapore/story/more-patients-living-out-final-days-home-20130623

Hospice New Zealand launches guidelines for managers of volunteer services

NEW ZEALAND | Scoop.co.nz – 19 June 2013 – "With more than 13,000 people spending more than 480,000 hours volunteering for hospice every year, we need to ensure their experience is satisfying and meaningful. That is why we have developed *The Hospice Guidelines for Managers of Volunteer Services* to support and resource the people responsible for managing the large volunteer teams," explains Mary Schumacher, CEO, Hospice NZ. The Guidelines are a practical resource covering topics such as interviewing, health and safety, evaluation and positive management – all within a hospice context. Sitting within the *Guidelines* are templates for job descriptions, application forms, and referee reports for Hospice New Zealand members to personalise to their individual service needs. http://community.scoop.co.nz/2013/06/guidelines-for-managers-of-volunteer-services-launched/

N.B. Hospice New Zealand website: http://www.hospice.org.nz/



Barry R. Ashpole

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

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

Use of inpatient specialist palliative care services in England increases

U.K. (ENGLAND) | National Council for Palliative Care – 19 June 2013 - A Public Health England (PHE) commissioned report shows there has been an increase in the availability and use of inpatient specialist palliative care beds in England. The report, published by the National Council for Palliative Care and PHE's National End of Life Care Intelligence Network, shows the mean number of patients seen in inpatient units is at its highest level in more than ten years, with the average number of available beds (those that are or can be used) also at a high. The proportion of occupied beds has remained high at 74.8%, reflecting efficient use of beds, although there are considerable variations across the country. The report also finds people receiving specialist palliative care are more likely to be able to die at home – the place where most people say that want to die. It also shows specialist palliative care services have made considerable progress in opening up to non-cancer patients, but there remains a long way to go. http://www.endoflifecare-intelligence.org.uk/resources/publications/survey

Of related interest:

- NATIONAL COUNCIL FOR PALLIATIVE CARE | Online 20 June 2013 'Deprivation and end of life care.' New analysis from the Office for National Statistics from the National Bereavement Survey 2011 (VOICES) has been published which shows an apparent link between deprivation and the quality of end of life care received. Significantly more bereaved respondents of patients living in the least deprived areas rated the standard of overall end of life care as excellent (44%) compared with respondents of patients living in the most deprived areas (39%). http://www.ncpc.org.uk/news/%5Btitle-raw%5D
 - National Bereavement Survey (VOICES) by Area Deprivation, 2011, Office for National Statistics, June 2013. http://www.ons.gov.uk/ons/dcp171778 315264.pdf%20
- U.K. (ENGLAND) | Greater London Authority Conservatives Accessed 20 June 2013 'Unheard Voices: The Liverpool Care Pathway.' Data from 21 London health trusts shows: 38% could not say how many patients were on The Liverpool Care Pathway; 81% could not provide the number of patients who were removed from the pathway and/or survived; 81% could not give the longest and shortest periods that patients were on the pathway; 38% could not provide any of the requested information on patients on the pathway. http://glaconservatives.co.uk/campaigns/the-liverpool-care-pathway/

Noted in Media Watch, 17 June 2013, #310 (p.8)

Specialist Publications

[Response to] 'We need an alternative to The Liverpool Care Pathway for patients who might recover' (p.9), in British Medical Journal.

- U.K. (ENGLAND) | The Daily Express 16 June 2013 'London hospitals fail to keep records on thousands of terminally ill patients.' Despite the controversy surrounding the [Liverpool Care] Pathway, research indicates many hospitals lack even the most basic information on how many patients are on it. http://www.express.co.uk/news/health/407914/London-hospitals-fail-to-keep-records-on-thousands-of-terminally-ill-patients
- U.K. (ENGLAND) | *The Guardian* 20 June 2013 'Quality of family doctors' end-of-life care varies significantly, analysis shows.' The chances of receiving excellent end-of-life care from GPs in England vary significantly according to where you live, an analysis by the Office for National Statistics has found. The verdict of bereaved carers on the way family doctors treat patients in the last three months of their lives shows 37% of relatives or friends in the least deprived areas rated the care excellent compared with 30% in the most deprived. The difference in the quality of end-of-life care received is not statistically significant in any other service... Numbers were too low for those who died in hospices to provide reliable data. http://www.guardian.co.uk/society/2013/jun/20/quality-end-of-life-care

Cont.

- U.K. | The Daily Telegraph 19 June 2013 'Call to stop 'lottery' of end-of-life care.' Terminally ill patients are suffering wildly varying standards of end-of-life care depending on their disease, postcode and ethnicity, a new report has found.¹ The "unacceptable" differences mean that some patients receive an early diagnosis and help in ensuring their wishes are met, while others have no access to support and die in hospital rather than at home. A nationally co-ordinated system involving more choice for patients is needed to eliminate the "lottery" and provide more dignity in death, the report said. Cancer sufferers receive the earliest and most reliable diagnoses and have access to better support programmes than people with other diseases. http://www.telegraph.co.uk/health/elderhealth/10128215/Call-to-stop-lottery-of-end-of-life-care.html
 - People's final journey must be one of their choosing ... Ways and Means, Demos, U.K., June 2013. http://www.demos.co.uk/files/Ways and Means - web.pdf?1371587652
- U.K. (England) | Help the Hospices 18 June 2013 'Hospices losing out under complex new commissioning arrangements.' Hospices across England are caught in "a cat's cradle" of complex commissioning and contracting arrangements under new National health Service structures, which are hindering hospices and saddling many with additional costs. A Help the Hospices survey showed that under the new arrangements commissioning has become more complex. A quarter of hospices surveyed said they were working with four or more statutory commissioners, with 38% working with three or more. One hospice reported working with eight separate commissioners. The financial impact of the new commissioning and contracting arrangements on all hospices in England, primarily from new data reporting requirements, is estimated to be at least £3.2 million. http://www.helpthehospices.org.uk/media-centre/press-releases/hospices-losing-new-commissioning-arrangements/

N.B. To download a copy of 'The Commissioning of Hospice Care in England in 2013/14,' scroll down to foot of webpage.

Twenty centres for palliative care to be opened in Serbia by year-end

SERBIA | Balkans.com – 18 June 2013 – Serbia's Minister of Health, Slavica Djukic-Dejanovic, and Head of the EU [European Union] Delegation to Serbia, Vincent Degert, delivered [the] keys to 54 vehicles for palliative care to directors of 52 health centres. Djukic-Dejanovic ... recalled that as part of this cooperation between the EU and the Ministry of Health, 800 employees in the health sector and gerontology received training on the importance of palliative care, as well as 59 social workers. The palliative medicine course was introduced as an optional subject at four medical faculties in Serbia, the Minister pointed out and added that at this moment four centres for palliative care are fully operational, while by the end of the year there should be 20 of them. http://www.balkans.com/open-news.php?uniquenumber=176830

Noted in Media Watch, 6 June 2011, #204 (p.6):

SERBIA | Balkan Business News (Nicosia, Cyprus)— 31 May 2011 – 'Institute for Oncology & Radiology of Serbia a centre for palliative care...' Plans for the development of palliative care services are announced. http://www.balkans.com/open-news.php?uniquenumber=106938

Assisted (or facilitated) death

Representative sample of recent news media coverage:

EUROPE | The National Post (Canada) – 19 June 2013 – 'Belgium on the verge of making euthanasia more accessible for gravely ill children.' The Belgian parliament is reportedly on the verge of passing legislation that would allow people under 18 suffering from incurable illness to consent to euthanasia. In The Netherlands, a national physicians' group has issued guidelines that say parents' distress can justify hastening the demise of already dying newborns. The Royal Dutch Medical Association's policy applies to babies born with severe congenital defects who have been removed from life support because it was considered futile. http://news.nationalpost.com/2013/06/19/belgium-on-verge-of-making-euthanasia-accessible-for-very-ill-children/

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

End-of-life treatment decision making: American Indians' perspective

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 17 June 2013 – Scarce knowledge about this population's perspective regarding end-of-life treatments has resulted in health care providers (HCPs) functioning at less than optimum levels. Patient and family [study] participants generally stated the physicians made the treatment decisions for them, while HCPs believed patients participated in informed autonomous treatment decision making. Both parties ... were not aware of American Indian's psychological aspect that interfered with the exercise of the right of informed consent. This additional understanding would benefit them in order to result in ethically and legally sound practice of patient's autonomous treatment decision making. http://ajh.sagepub.com/content/early/2013/06/17/1049909113489592.abstract

Noted in Media Watch, 28 November 2011, #229 (p.3):

■ INDIAN COUNTRY TODAY | Online – 21 November 2011 – 'A look at end-of-life care issues for Native Americans.' More than 4 million people in the U.S. identify themselves as either American Indian or Alaska Native (Al/AN), a diverse group of people who come from more than 500 tribes. Their access to palliative care, hospice, and end-of-life services lags behind the rest of the nation. http://indiancountrytodaymedianetwork.com/2011/11/21/a-look-at-end-of-life-care-issues-for-native-americans-63942

Media Watch posted on Palliative Care Network-e Website

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

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.

Building a compassionate community: Developing an informed and caring workplace in response to employee bereavement

BEREAVEMENT CARE, 2013;32(1):4-10. When an employee suffers a bereavement, the responses of colleagues and line managers can have long lasting effects. Critical elements in shaping this response may be human resource policies and their interpretation; these can influence not only the process of grief for the individual, but can also have a long term impact on the health of organisations themselves. This small interview study with recently bereaved employees indicates that the ways in which they perceive they are treated following the death of a loved one can deeply influence their ongoing relationship within the organisation. Handled well, these difficult episodes can instil a commitment from the employee towards work and aid in the grieving process. http://www.tandfonline.com/doi/full/10.1080/02682621.2013.779819

Of related interest:

■ AGING HEALTH, 2013;9(1):103-114. 'Anticipatory grief therapy for older persons nearing the end of life.' The reality of anticipatory grief (AG) in older patients facing the end of life is easily overlooked with little provision of psychosocial support, especially for those aging in institutions without integrated palliative care services. This article discusses the challenges that AG poses for the older patients, as well as the desired therapeutic outcomes through using this approach. Beneficial therapeutic approaches for AG-related constructs will be reviewed, with recommendations to design interventions that target the AG of older patients facing different advanced conditions. http://www.futuremedicine.com/doi/abs/10.2217/ahe.12.74

Independent commission will look at split between health and social care in England

BRITISH MEDICAL JOURNAL | Online – 19 June 2013 – An independent commission to consider the future of health and social care in England has been set up by the health think tank the King's Fund, which aims to publish the findings in time for the 2015 general election. It will be chaired by Kate Barker, an economist best known for a review published by the Treasury in 2004 that called for a massive increase in house building in England. Although supported by the fun... Barker's commission is free to reach any conclusion it finds most persuasive. It would, however, be a surprise if it disagreed with the fund's often expressed belief that the two systems of health-care and social care – one free to all, the other means tested – need closer integration and a common purpose. http://www.bmj.com/content/346/bmj.f3973

N.B. The King's Fund Commission will produce an interim report in early 2014 and a final report by September 2014. Commission website: http://www.kingsfund.org.uk/projects/commission-future-health-and-social-care-england

Noted in Media Watch, 17 June 2013, #310 (p.13):

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 11 June 2013 – 'Factors that promote and hinder joint and integrated working between health and social care services: A review of research literature.' The findings of the review suggest that there is some indication that recent developments, in particular the drive to greater integration of services, may have positive benefits for organisations as well as for users and carers of services. http://onlinelibrary.wiley.com/doi/10.1111/hsc.12057/abstract

Noted in Media Watch, 13 May 2013, #305 (p.13):

■ HEALTH SERVICE JOURNAL | Online – 8 May 2013 – 'Redesigning end of life care in the community.' The challenges for the health and social care system in our rapidly ageing society and the pressure associated with ongoing public spending constraints are clear for all to see. Faced with these twin challenges, we can either stand by and oversee a gradual decline in the quality of care provided or we can seize the opportunity to fundamentally change the way we do things. http://www.hsj.co.uk/home/innovation-and-efficiency/redesigning-end-of-life-care-in-the-community/5057553.article?blocktitle=Resource-Centre&contentID=8630

Evidence on community based care for people with long term conditions is lacking, say experts

BRITISH MEDICAL JOURNAL | Online – 19 June 2013 – No good evidence exists that shifting the focus of National Health Service care away from hospitals to the community for people with long term conditions makes clinical or economic sense, MPs have been told. Serious questions should be asked about winding down or merging hospitals while investing more in primary and community care, experts in economics and research told MPs on the parliamentary health select committee. The committee held the first evidence session of its inquiry into the management of long term conditions on 18 June. MPs asked witnesses their opinion on the view that better quality and more economic care for people with long term conditions would be achieved only by greater integration of [health and social services]. http://www.bmj.com/content/346/bmj.f3987

Of related interest:

- BMJ SUPPORTIVE & PALLIATIVE CARE | Online 20 June 2013 'Is home-based palliative care cost-effective? An economic evaluation of the Palliative Care Extended Packages at Home (PEACH) pilot.' The results of this small pilot study point to the potential of PEACH as a cost-effective end-of-life care model relative to usual care. http://spcare.bmj.com/content/early/2013/06/20/bmjspcare-2012-000361.abstract
- PALLIATIVE MEDICINE | Online 18 June 2013 'Are family physician visits and continuity of care associated with acute care use at end-of-life? A population-based cohort study of homecare cancer patients.' The results of this study demonstrate an association between increased family physician continuity of care and decreased odds of several acute care outcomes in late life, controlling for homecare nursing and other covariates. http://pmj.sagepub.com/content/early/2013/06/18/0269216313493125.abstract

[Response to] 'We need an alternative to The Liverpool Care Pathway for patients who might recover'

BRITISH MEDICAL JOURNAL | Online (Letter to the Editor) – 18 June 2013 – I'm afraid this article simply highlights the lack of understanding that many healthcare professionals still have of The Liverpool Care Pathway (LCP). It's no wonder the *Daily Mail* has had a field day when it seems even our own colleagues persist in disseminating inaccurate assumptions. My biggest concern with author's article is the statement that death is "an inevitable outcome" of the pathway. It is not. Both personal experience and published literature show that some patients improve and are taken off the pathway, often surviving for days, weeks, months or even years afterwards! Furthermore, life is not black and white. Only a foolish or naive clinician would claim 100% certainty in predicting when a patient was "unquestionably within the last days" of life. We must therefore be able to make balanced clinical assessments regarding our patients' realistic chance of recovery. The LCP should be used when that assessment points towards a diagnosis of "dying," not a diagnosis of "deteriorating." Although there will always be exceptions to the rule, if we genuinely believe there is a reasonable chance of recovery then we should not be considering the LCP in the first place. http://www.bmj.com/content/346/bmj.f3702/rr/650387

Noted in Media Watch, 17 June 2013, #310 (p.12):

BRITISH MEDICAL JOURNAL | Online – 11 June 2013 – 'We need an alternative to The Liverpool Care Pathway for patients who might recover.' Having a pathway for all situations is an obsession of today's medicine. Sometimes this has led to a pathway that was designed for one situation being adapted or used in another – and not always to good effect. http://www.bmj.com/content/346/bmj.f3702

N.B. A representative sample of recent articles on The Liverpool Care Pathway noted in Media Watch are listed in the 10 June 2013 (#309) issue of the weekly report (pp.11-12).

Early integration of palliative care services with standard oncology care for patients with advanced cancer

CA: A CANCER JOURNAL FOR CLINICIANS | Online – 17 June 2013 – Accumulating data show that the introduction of palliative care services at the time of diagnosis of advanced cancer leads to meaningful improvement in the experiences of patients and family caregivers by emphasizing symptom management, quality of life, and treatment planning. In this review article, the rationale and evidence base for this model of early palliative care services integrated into standard oncology care are presented. In addition, the implications and limitations of the existing data to 1) elucidate the mechanisms by which early palliative care benefits patients and families; 2) guide the dissemination and application of this model in outpatient settings; and, 3) inform health care policy regarding the delivery of high-quality, cost-effective, and comprehensive cancer care are discussed. http://onlinelibrary.wiley.com/doi/10.1002/caac.21192/full

Advance care planning for institutionalised older people: An integrative review of the literature

INTERNATIONAL JOURNAL OF OLDER PEOPLE NURSING | Online – 20 June 2013 – Based on 23 articles published between 1999 and 2012, this review distinguishes theoretical from empirical research and presents a classification of studies based on their methodological robustness (descriptive, qualitative, associative or experimental). It thus provides nursing professionals with evidence-based information in the form of a synthetic vision and conceptual framework to support the development of innovative care practices in the end-of-life context. While theoretical work places particular emphasis on the impact of changes in practice on the quality of care received by residents, empirical research highlights the importance of communication between the different persons involved about care preferences at the end of life and the need for agreement between them. http://onlinelibrary.wiley.com/doi/10.1111/opn.12033/abstract

Quality of end-of-life care of long-term nursing home residents with and without dementia

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 17 June 2013 – Overall hospice use [in the U.S.] increased from 25.6% in 2003 to 35.7% in 2007. During this time, hospice use for decedents with dementia increased from 25.1% to 36.5%, compared with an increase from 26.5% to 34.4% for decedents without dementia. The rate of in-hospital deaths remained virtually unchanged. Within the same facility, decedents with dementia were significantly more likely to use hospice and less likely to die in a hospital. Decedents in NHs [nursing homes] with higher dementia prevalence, regardless of individual dementia status, were more likely to use hospice. Although significantly more residents with dementia now receive hospice care at the end of life, the quality evaluation and monitoring of hospice programs have not been systematically conducted... http://onlinelibrary.wiley.com/doi/10.1111/jgs.12330/abstract

Of related interest:

PALLIATIVE AND SUPPORTIVE CARE | Online – 18 June 2013 – 'Understanding the needs of family caregivers of older adults dying with dementia: Literature search.' Understanding the scope of dementia family caregivers needs help further our understanding of how these needs may impact the delivery of palliative care services, and assists in developing a model of care for those dying from dementia and for their family caregivers. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8939746&fulltextType=RA&fileId=S1478951513000461

Noted in Media Watch, 6 May 2013, #304 (p.7):

ALZHEIMER'S & DEMENTIA, 2013;9(2):208 -245. '2013 Alzheimer's disease [U.S.] facts and figures.' An estimated 5.2 million Americans have Alzheimer's disease (AD). Between 2000-2010, the proportion of deaths resulting from heart disease, stroke and prostate cancer decreased 16%, 23%, and 8%, respectively ... the proportion resulting from AD increased 68%. http://www.alzheimersanddementia.com/article/S1552-5260(13)00076-9/fulltext#abstract

Frailty consensus: A call to action

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS, 2013;14(6):392-397. A consensus group consisting of delegates from six major international, European and U.S. societies created four major consensus points on a specific form of frailty: physical frailty: 1) Physical frailty is an important medical syndrome. The group defined physical frailty as "a medical syndrome with multiple causes and contributors that is characterized by diminished strength, endurance, and reduced physiologic function that increases an individual's vulnerability for developing increased dependency and/or death": 2) Physical frailty can potentially be prevented or treated with specific modalities, such as exercise, protein-calorie supplementation, vitamin D, and reduction of polypharmacy: 3) Simple, rapid screening tests have been developed and validated, such as the simple FRAIL scale, to allow physicians to objectively recognize frail persons: and, 4) For the purposes of optimally managing individuals with physical frailty, all persons older than 70 years and all individuals with significant weight loss due to chronic disease should be screened for frailty. http://www.jamda.com/article/S1525-8610(13)00182-5/abstract

Noted in Media Watch, 21 January 2013, #289 (p.8):

■ JOURNAL OF NURSING EDUCATION & PRACTICE, 2013;3(7):75-91. 'When frailty should mean palliative care.' The aim of this work is to assist physicians in providing proper care for the frail elderly. It consists in a systematic review of the literature available, intended answer the following questions: 1) Is frailty an appropriate indication for the instatement of palliative care? 2) When is the right moment to instate palliative care for the frail elderly subject? 3) What tools are available to assist care teams? 4) Are there efficient organisational models that integrate the frail elderly into palliative care? There are answers to these questions. But the level of evidence is low. It can be concluded that frailty is an indication for the instatement of palliative care. http://www.sciedu.ca/journal/index.php/jnep/article/view/1689

How to measure the international development of palliative care? A critique and discussion of current approaches

JOURNAL OF THE PAIN & SYMPTOM MANAGEMENT | Online – 17 June 2013 – The aim of this article was to provide a critical comparative analysis of methodological approaches used to assess the development and status of palliative care services and infrastructure at an international level. Reviewed reports were found to differ in adopted methodologies and provided uneven amounts of methodological information. Five major methodological limitations were identified (lack of theory, use of experts as source of information, grey literature, difficulties in ranking, and the problematic nature of data on service provision). A set of recommendations on how to deal with these issues in future research is provided. Measuring the international development of palliative care is a difficult and challenging task. The results of this study could be used to improve the validity of future research in this field. http://www.jpsmjournal.com/article/S0885-3924(13)00230-3/abstract

Noted in Media Watch, 22 April 2013, #302 (p.9):

- CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online 6 April 2013 'Palliative care program development: An international perspective.' In this edition of Current Opinion in Supportive & Palliative Care, we review the different models of palliative care delivery, with perspectives from the U.K., the U.S., Japan, India, and sub-Saharan Africa. The five models of palliative care across all care settings remains a priority and also show that we can learn as much from the developing models in resource-poor nations as we can from more well established programs. http://www.ncbi.nlm.nih.gov/pubmed/23572160
 - 1. Contents page: http://journals.lww.com/co-supportiveandpalliativecare/toc/publishahead

Noted in Media Watch, 19 July 2010, #158 (p.3):

■ ECONOMIST INTELLIGENCE UNIT (EIU) | Online – 14 July 2010 – 'The U.K. has the highest quality of death.' While more than 100million patients and family care-givers worldwide need palliative care annually less than 8% of this number actually receives it, according to the Worldwide Palliative Care Alliance. With this in mind, the EIU devised a "quality of death" index to rank countries according to their provision of end-of-life care. Commissioned by the Lien Foundation, the index measured the current environment for end-of-life care services across forty countries. http://graphics.eiu.com/upload/QOD main final edition Jul12 toprint.pdf

A framework for understanding moral distress among palliative care clinicians

JOURNAL OF PALLIATIVE MEDICINE | Online – 18 June 2013 – In the clinical context, responses to distressing events are thought to include four dimensions: empathy (emotional attunement), perspective taking (cognitive attunement), memory (personal experience), and moral sensitivity (ethical attunement). These dynamically intertwined dimensions create the preconditions for how clinicians respond to a triggering event instigated by an ethical conflict or dilemma. The authors postulate if the four dimensions are highly aligned, the intensity and valence of emotional arousal will influence ethical appraisal and discernment by engaging a robust view of the ethical issues, conflicts, and possible solutions and cultivating compassionate action and resilience. http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0490

Spirituality in end-of-life and palliative care: Theory, research, and practice dimensions for social work

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE, 2013;9(2-3):111. Recognition of the importance of spirituality in the lives of individuals and families at the end of life has been growing steadily. This special thematic issue of the journal brings together manuscripts that give just a snapshot of some theoretical and practice perspectives in which spirituality plays a key role. http://www.tandfonline.com/doi/full/10.1080/15524256.2013.793988

N.B. Journal contents page: http://www.tandfonline.com/toc/wswe20/current

Of related interest:

- BRITISH JOURNAL OF SOCIAL WORK | Online 19 June 2013 'Spirituality and religion in end-of-life care ethics: The challenge of interfaith and cross-generational matters.'

 Religion and spirituality can be important coping mechanisms for meeting these challenges. However, although many people may want spirituality incorporated as a component of their care, spiritual needs are not always recognised or supported by the existing social care and medical systems. To address the need for more information on these issues, we present two social work cases that draw from our clinical experiences among patients with life-limiting disease conditions. http://bjsw.oxfordjournals.org/content/early/2013/06/19/bjsw.bct110.abstract
- OMEGA JOURNAL OF DEATH & DYING, 2013;67(1-2):37-41. 'Facilitating the provision of quality spiritual care in palliative care.' In 2009, a consensus panel was convened to address the important issue of integrating spirituality in palliative care, which led to renewed efforts to focus on spiritual care as a critical component of quality palliative care. This project is a combination of advocacy for the importance of spiritual care, training chaplains, seminarians, community clergy, and healthcare professionals in palliative care, and creating a spiritual care curriculum which can be self-taught or taught to members of trans-disciplinary teams. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,4,30:journal,1,264;linkingpublicationresults,1:300329,1
- PSYCHO-ONCOLOGY | Online 17 June 2013 'Spiritual beliefs near the end of life: A prospective cohort study of people with cancer receiving palliative care.' Results [of this study] suggest that although religious and spiritual beliefs might increase marginally as death approaches, they do not affect levels of anxiety or depression in patients with advanced cancer. http://onlinelibrary.wiley.com/doi/10.1002/pon.3313/abstract

Cont.

Noted in Media Watch, 25 June 2012, #259 (p.9):

• ARCHIVE FOR THE PSYCHOLOGY OF RELIGION, 2012;34(1):63-81. 'Six understandings of the word 'spirituality' in a secular country.' Spirituality is a growing research theme, especially in relation to health issues. The term is often poorly defined and one's understanding is often so broad that it becomes a mere frame word devoid of meaning. It is concluded that a common understanding of the term spirituality does not exist, at least in a modern secular setting. http://www.ingentaconnect.com/content/brill/arp/2012/00000034/00000001/art00005

N.B. This issue of the *Archive for the Psychology of Religion* focuses on spirituality. Journal contents page: http://booksandjournals.brillonline.com/content/15736121.

Towards better support for family carers: A richer understanding

PALLIATIVE MEDICINE, 2013;27(7):579-580. This special edition of Palliative Medicine aims to address the important topic of how best to support ... "family carers" who provide care to patients during advanced illness and through the process of dying. It is widely recognised that these people have an essential role in providing physical care, emotional and social support; financial resources; advocacy and anticipatory care and in negotiating and coordinating care during the final phases of life. The presence of family carers who are able and willing to provide care is essential to facilitate important patient choices, such as place of care and place of death. It is a challenging and demanding role, which few people aspire to, but which many will have thrust upon them, in often difficult circumstances and following a "crisis." Undertaking this role may have physical, psychological, social and financial consequences for carers, which outlast their period of care and may influence their bereavement. Yet remarkably until relatively recently, there has been little academic interest in how family carers adapt to and manage their role in caring for those who are facing death. http://pmj.sagepub.com/content/27/7/579.extract

N.B. Journal contents page: http://pmj.sagepub.com/content/current

Of related interest:

- PALLIATIVE & SUPPORT CARE | Online 17 June 2013 'Mindfulness in informal caregivers of palliative patients.' Mindfulness [among study participants] was a significant predictor of improvement in psychological distress, meaning in life, and quality of life three months after the intervention. Existential Behavioural Therapy effects were partly mediated by mindfulness.http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8938683&fulltextType=RA&fileId=S1478951513000400
- PLoS ONE | Online 6 June 2013 'Caregiver Evaluation of the Quality of End-Of-Life Care (CEQUEL) scale: The caregiver's perception of patient care near death.' End-of-life (EOL) measures are limited in capturing caregiver assessment of the quality of EOL care. Because none include caregiver perception of patient suffering or prolongation of death, the authors sought to develop and validate the Caregiver Evaluation of Quality of End-of-Life Care (CEQUEL) scale to include these dimensions of caregiver-perceived quality of EOL care. http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0066066

British Medical Association to review DNR orders guidance

PULSE (U.K.) | Pulse – 21 June 2013 – The BMA [British Medical Association] is reviewing its guidance on resuscitating patients when their heart or breathing stops following high profile cases involving DNR orders. The current BMA guidance on DNR orders – decisions relating to cardio-pulmonary resuscitation – was established in October in partnership with the Royal College of Nursing and the Resuscitation Council (U.K.). The BMA said it could not give details about which specific areas of its current guidance it is reviewing. http://www.pulsetoday.co.uk/news/clinical-news/bma-to-review-dnr-orders-quidance/20003373.article#.UcbX0ztwomY

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Media Watch Online

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: http://aphn.org/?s=media+watch

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

Australia

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

Canada

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

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

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

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

ONTARIO | Toronto Central Hospice Palliative Care Network: http://www.tcpcn.ca/uncategorized/media-watch-309-june-10-2013

Europe

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

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

International

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

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

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

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