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.

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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to <u>Specialist Publications</u> and 'A systematic review of family meeting tools in palliative and intensive care settings' (p.7), in *American Journal of Hospice & Palliative Medicine*.

U.S.A.

Care planning

Building a Khan Academy for health care

THE NEW YORK TIMES | Online - 29 July 2015 - Doctors don't like to talk about death, and they often avoid doing so. Most physicians ... never studied palliative care in medical school and were rarely trained in how to communicate with patients. The recent expansion of the field of palliative medicine, with doctors who are experts on having these discussions, is a giant step in the right direction. But the growth of this specialty has not kept up with the need: There are 4,400 such doctors in the U.S. today, but the need is estimated to be as high as 18,000 physicians. Incentives such as student loan forgiveness, higher baseline salaries and more robust insurance reimbursements would encourage more students to consider the specialty as a profession. But it would take time for society to reap the benefits. Recently Medicare announced plans to reimburse doctors for having advance care planning conversations with patients. This is an important start. But it's not enough to simply

Extract from The New York Times article

Unfortunately, most Americans live and die in a health care system that does not offer patients and families the educational tools they need to navigate care at the end of life. If that were true of cancer therapies, there would be an uproar and outrage. How many patients will we allow to die in our health care system without their being fully informed of their options?

Conversation Ready: A Framework for Improving End-of-Life Care

MASSACHUSETTS | Institute for Healthcare Improvement – 31 July 2015 – The Institute's white paper includes a framework built on five core principles to help healthcare organizations engage patients in conversations about their wishes for end-of-life care, steward that information, and respect those wishes at the appropriate time. http://www.healinghealth.com/news/5-principles-for-improving-end-of-life-care/

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reimburse for these discussions, which are not one-time exchanges, but rather a process over time. Neither is it realistic to expect most doctors who have never been trained to have these dialogues to all of a sudden be experts, which studies have suggested is difficult. We need to make sure that these exchanges are high-quality, informed, shared decision-making encounters where patients understand each of their options along with the risks and benefits. http://opinionator.blogs.nytimes.com/2015/07/29/building-a-khan-academy-for-health-care/? r=0

Families provided \$470 billion in unpaid care to loved ones in 2013

REUTERS | Online – 29 July 2015 – Family caregivers in the U.S. provided an estimated \$470 billion in unpaid medical support and other services to their loved ones in 2013, up from \$450 billion five years earlier, according to a recent report from the American Association of Retired Persons (AARP). Those unpaid services are worth more than total Medicaid spending for 2013 and also more than annual combined sales that year from the four largest U.S. technology companies (Apple, Hewlett Packard, IBM and Microsoft), researchers say. An estimated 40 million family caregivers worked an average of 18 unpaid hours each week helping spouses, parents, partners and other loved ones, AARP estimated. http://www.reuters.com/article/2015/07/29/us-health-caregiving-value-idUSKCN0Q32K420150729

 'Valuing the Invaluable: 2015 Update,' AARP Public Policy Institute, July 2015. http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf

N.B. Scroll down to <u>International</u> and 'Unpaid cancer carers save taxpayers £219 million a year – but how long can it carry on?' (p.3), in the U.K. newspaper *The Mirror*.

"Jaw-dropping": Medicare deaths, hospitalizations AND costs reduced

USA TODAY | Online – 27 July 2015 – The U.S. health care system has scored a medical hat trick, reducing deaths, hospitalizations and costs, a new study shows. Mortality rates among Medicare patients fell 16% from 1999 to 2013. That's equal to more than 300,000 fewer deaths a year in 2013 than in 1999, said cardiologist Harlan Krumholz, lead author ... "It's a jaw-dropping finding," Krumholz said. "We didn't expect to see such a remarkable improvement over time." Researchers based the study on records from more than 68 million patients in Medicare, the federal health insurance program for people age 65 and older. Researchers were able to find additional information about hospitalization rates and costs among Medicare's traditional "fee-for-service" program, in which doctors and hospitals are paid for each procedure or visit. Among fee-for-service patients, hospitalization rates fell 24%, with more than 3 million fewer hospitalizations in 2013 than 1999... When patients were admitted to the hospitals, they were 45% less likely to die during their stay; 24% less likely to die within a month of admission; and 22% less likely to die within a year... Costs for hospitalized patients also fell by 15% among fee-for-service patients. http://www.usatoday.com/story/news/2015/07/27/medicare-mortality-costs-study/30757669/

 'Mortality, hospitalizations, and expenditures for the Medicare population aged 65 years or older, 1999-2013,' *Journal of the American Medical Association*, 2015;314(4):355-365. http://jama.jamanetwork.com/article.aspx?articleid=2411282

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.13.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

CALIFORNIA | The Washington Post – 27 July 2015 – 'Judge tosses lawsuit seeking fatal drugs for terminally ill.' A judge ... dismissed a lawsuit against the state on behalf of three terminally ill Californians seeking doctor-prescribed fatal medication. San Diego Superior Court Judge Gregory Pollack said his court is not unsympathetic to their plight, but lawmakers – not a judge – would need to change the law barring such prescriptions. Pollack said ... that the current law that makes it a felony to assist a suicide in any way is constitutional and so he does not have the power to suspend its enforcement. http://www.washingtonpost.com/national/health-science/judge-tosses-lawsuit-seeking-fatal-drugs-for-terminally-ill/2015/07/27/a0841ca6-34a2-11e5-b835-61ddaa99c73e_story.html

International

End-of-life care in England & Wales

Unpaid cancer carers save taxpayers £219 million a year – but how long can it carry on?

U.K. (England & Wales) | The Mirror - 30 July 2015 - Selfless volunteers who care for cancer-stricken family members are saving taxpayers £219 million a year, a report has found. The figure was worked out by health experts - who've warned the government could be facing a crisis as the number of patients continues to rise. They called on the Tories to open up more funds because the U.K.'s increasingly ageing population will mean there will be fewer unpaid carers able to meet demand. Their study ... said unpaid carers account for what would be a third of the cost of end-of-life care for people with breast, lung, colorectal and prostate cancers. Those account for around 45% of all cancer-related deaths in England & Wales. They warned there will soon be a much larger demand for state-funded end-of-life care that could lead to more people in need missing out. http://www.mirror.co.uk/news/uknews/unpaid-cancer-carers-save-taxpayers-6162207

Male caregivers may be less likely to ask for help

U.K. | Reuters – 31 July 2015 – Among unpaid, informal caregivers of older people with illness or disability, male caregivers in particular can be ambivalent about asking for help, according to a new review. Caregivers are often family or close friends. Most are women. In the U.K., for example, 58% of informal caregivers are female. But that leaves more than 40% who are men. It can be harder to study male caregivers because they are less likely to identify themselves that way. http://www.reuters.com/article/2015/07/31/ushealth-men-caregiving-idUSKCN0Q52KB20150731

1. 'Barriers and facilitators for male carers in accessing formal and informal support: A systematic review,' *The European Menopause Journal*, 19 July 2015. http://www.maturitas.org/article/S0378-5122(15)30020-7/abstract

'Estimating the cost of caring for people with cancer at the end of life: A modelling study,' Palliative Medicine, 21 July 2015. The cost to formal care services of replacing this care with paid care giving would be significant and demand for care will increase as the the population ages. http://pmj.sagepub.com/content/early/2015/07/27/0269216315595203.full.pdf+html

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Palliative Care: Fact Sheet #402 (July 2015): http://www.who.int/mediacentre/factsheets/fs402/en/

Of related interest:

U.K. (England) | The Guardian – 26 July 2015 – 'Jeremy Hunt's u-turn on social care "cost taxpayer £100 million." The health secretary, Jeremy Hunt, faces a growing backlash after quietly shelving a key Tory manifesto commitment to cap care costs for the elderly, as experts claimed that the policy fiasco has cost taxpayers up to £100 million. Hunt has announced that the plan to limit care bills from next year to £72,000 for the over-65s and for younger adults with disabilities has been delayed until 2020 – despite the fact it was trumpeted by the Conservatives in the run-up to the general election. While Hunt insisted that his department was still fully committed to the policy – which ministers had claimed would prevent old people having to sell their homes to pay care bills – most experts believe that it has, effectively, been abandoned. http://www.theguardian.com/politics/2015/jul/25/jeremy-hunt-backlash-axing-elderly-care-cappolicy

Noted in Media Watch, 23 May 2015, #402 (p.5):

U.K. | The Economist – 14 March 2015 – 'Nobody wants to insure themselves against the cost of end-of-life care.' People with assets under £23,250 get most of their residential care paid for, but everyone else is more-or-less on their own, with the unluckiest facing bills as high as £200,000. The government is moving to change that. Next year it will put a cap of £72,000 on the sum that a person will have to pay towards care, and will raise the means-testing threshold ... to £118,000. https://www.economist.com/news/britain/21646238-nobody-wants-insure-themselves-against-cost-end-life-care-forever-young

End-of-life care in Scotland

New national CPR policy to be unveiled in September

U.K. (Scotland) | *The Herald* (Glasgow) – 30 July 2015 – A new national policy on the use of CPR on terminally-ill patients is expected ... in September. Health Secretary Shona Robison said the review and update of policy is part of efforts to "ensure that palliative and end-of-life care is delivered to a high standard, in every situation, right around the country." Scotland became the first country in Europe to put in place a national policy for CPR decision-making and communication in the National Health Service in 2010. A recent legal ruling and changes in U.K.-wide good practice guidance mean this has been reviewed. The update emphasises the importance of engaging patients and their families about when resuscitation can be used for those nearing the end of life. http://www.heraldscotland.com/news/13520935.New national CPR policy to be unveiled in September/

- 'Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy,' The Scottish Government, May 2010. http://www.gov.scot/resource/doc/312784/0098903.pdf
- '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



End-of-life care in England

Dying care: "Improved" guidelines proposed

U.K. (England) | BBC News - 29 July 2015 -England's health watchdog has put forward new draft guidance to improve the care of adults in their last few days of life. 1 It comes after concerns that misuse of the previous system - The Liverpool Care Pathway - led to some patients being deprived of water and food. The guidelines encourage staff to involve patients and relatives in decisions and to communicate well. The Department of Health and charities welcomed the move. It involved a checklist to ensure patients were free from invasive procedures and medications that were no longer necessary. But it faced increasing opposition, with some describing it as a "tick-box exercise." And an independent review found some patients had been left thirsty and decisions sometimes taken by inexperienced staff.² The Liverpool Care Pathway was introduced in the late 1990s, in an attempt to ensure people had a dignified and comfortable death. While the National Institute for Health & Care Excellence acknowledges many failings were down to how the pathway was implemented - rather than a direct consequence of the document itself - the new draft proposals are designed to address these problems. The wide-ranging guidance intended for patients, relatives, hospitals, hospices and others involved in end-of-life care is open for public review until September 2015. http://www.bbc.com/news/health-33693619

Parliamentary & Health Service Ombudsman Report on end-of-life care: *The Times* newspapers' "correction and clarification"

U.K. (England) | The Times - 28 July 2015 - We stated that "hundreds of thousands of people endure a painful, undignified or lonely death because of 'appalling' end-of-life care right across the NHS" (20 May). This was incorrect and misleading. The report by the parliamentary and health service ombudsman, on which our statement was based, expressed the opinion that "there is potential to improve the experience of care in the last year and months of life for approximately 355,000 people" - the number of expected deaths each year; it did not state or suggest that the majority of NHS patients currently receive poor end-of-life care. "Appalling" was the reaction of the Department of Health to the twelve cases of very poor care cited by way of illustration in the ombudsman's report. http://www.thetimes.co.uk/tto/public/corrections/ar ticle4510066.ece

- 1. 'Dying Without Dignity,' Parliamentary & Health Service Ombudsman Report, published 20 May 2015. http://www.ombudsman.org.uk/ data/assets/pdf file/0019/32167/Dying without dignity report.pdf
- **N.B.** The ombudsman's report was noted in Media Watch, 25 May 2015, #411 (p.6). *The Times* amended the newspaper's original report, available at: http://www.thetimes.co.uk/tto/health/news/article4445579.ece
- 'Care of the Dying Adult: Draft Guideline Consultation,' National Institute for Health & Care Excellence, July 2015. (Consultation closes 9 September 2015; Anticipated publication December 2015) http://www.nice.org.uk/guidance/indevelopment/GID-CGWAVE0694/consultation/care-of-the-dying-adult-draft-guideline-consultation
- 'One Chance to Get it Right: Improving People's Experience of Care in the Last Few Days and Hours of Life,' Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.7)] https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations

How the news media reported on the National Institute for Health & Care Excellence guidelines:

- 'End of life guidelines revised after Scots rethink,' The Scotsman, 30 July 2015. http://www.scotsman.com/news/health/end-of-life-guidelines-revised-after-scots-rethink-1-3844631
- 'A good death: Can guidelines really help?' BBC News, 29 July 2015. http://www.bbc.com/news/health-33701339

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- 'Shock as doctors having to be TOLD to "give dying patients water," The Express, 29 July 2015. http://www.express.co.uk/news/uk/594629/NHS-doctors-nurses-told-give-dying-patients-water
- 'End-of-life judgments shouldn't be made by one doctor, says new guidance,' The Guardian, 29 July 2015. http://www.theguardian.com/society/2015/jul/29/end-of-life-decisions-doctor-new-guidance-nice
- 'Drugs to prevent "death rattle" of dying patients not justifiable if intention is only to reduce distress of relatives, says new guidelines,' The Independent, 29 July 2015. http://www.independent.co.uk/life-style/health-and-families/health-news/drugs-to-prevent-death-rattle-of-dying-patients-not-justifiable-if-intention-is-only-to-reduce-distress-of-relatives-says-new-guidelines-10422573.html
- 'National Health Service accused of an "industrialised" approach to death,' The Telegraph, 29 July 2015. http://www.telegraph.co.uk/news/nhs/11771193/NHS-accused-of-an-industrialised-approach-to-death.html
- 'Doctors warned don't leave patients to die if there's a chance they might survive,' *The Mirror*, 28 July 2015. http://www.mirror.co.uk/news/uk-news/doctors-warned-dont-leave-patients-6156040

Elder care in Australia

Ageing population not draining health budget, but reforms needed

AUSTRALIA | The Australian - 27 July 2015 - Modelling by David Cullen, chief economist of the commonwealth Department of Health, shows that changes in age structure have only made a small contribution to the recent growth in health expenditure. From 1995 to 2010, 17% of the rise in per capita health expenditure was due to the increased share of the population aged 65, while the fall in the share of the 0 to 14 age group reduced it by 8%. As a result, less than 10% of the net increment in per capita health spending could be explained by demography. What is true is that demographic trends could have a greater impact going forward. Indeed, the modelling suggests that were the health system to stay as it is, population ageing would account for a third of the overall growth in per capita health spending over the next 15 years. Already now, a 75-yearold costs the commonwealth, in outlays on the pharmaceutical and medical benefits schemes alone, some \$500 more each year than a 70-year-old does; as 70 to 80% of each cohort survive beyond age 80 (as compared to barely 40% in the mid-1960s), the challenge to future budgets seems obvious. But there are some crucial caveats. While a growing proportion of the population will live to very high ages, there is much less certainty about how that translates into the hospital costs the premiers complain about. http://www.theaustralian.com.au/opinion/columnists/ageingpopulation-not-draining-health-budget-but-reforms-needed/story-fn7078da-1227457722398

Noted in Media Watch, 5 September 2011, #200 (p.1):

CANADA (British Columbia) | CBC News – 29 August 2011 – 'Cost of aging population on health care "overblown." Fears Canada's aging population could lead to soaring health-care costs may be greatly exaggerated, say researchers, who suggest that the predicted "grey tsunami" may turn out to be more like a "grey glacier." Two studies by health economists at the University of British Columbia say other factors are driving up health-care costs – primarily the growing use of specialists, increasing diagnostic tests for the elderly, and the higher consumption of ever more costly drugs. http://www.cbc.ca/news/health/story/2011/08/29/grey-tsunamiaging-population.html

Facebook grants account life after death for U.K. users

U.K. (England, Northern Ireland, Scotland & Wales) | ITV News – 27 July 2015 – Facebook's 31 million users in the U.K. can now select a friend or loved one to curate their social media account in the event of their death. The designated "legacy contact" will be able to respond to new friend requests, update the profile picture and cover photo and write a pinned post on the profile. Previously Facebook had frozen an account of a deceased user to serve as a permanent "memorial". But the new feature allows users over the age of 18 to add (and remove) their chosen contact via their account security settings. http://www.itv.com/news/2015-07-27/facebook-grants-account-life-after-death-for-uk-users/

Noted in Media Watch, 16 February 2015, #397 (p.6):

U.K. | BBC News – 13 February 2015 – 'Facebook rolls out feature for users when they die.' Facebook has added a new setting that gives users the option of having their account permanently deleted when they die. Or, if they wish, they can choose to appoint a friend or family member to take control of some aspects of the account after their death. Facebook's legacy contact feature will initially only be available in the U.S. http://m.bbc.com/news/technology-31438707

Noted in Media Watch, 3 November 2014, #382 (p.13):

JOURNAL OF SOCIAL & PERSONAL RELATIONSHIPS | Online – 21 October 2014 – 'Death on Facebook: Examining the roles of social media communication for the bereaved.' This study examines the ways in which the social networking site Facebook was helpful and unhelpful to participants when someone they knew died. Analysis revealed three themes describing participants' experiences ... during bereavement: news dissemination, preservation, and community. http://spr.sagepub.com/content/early/2014/10/21/0265407514555272.abstract

Assisted (or facilitated) death

Representative sample of recent news media coverage:

NEW ZEALAND | TV3 (Auckland) – 27 July 2015 – 'Poll: Kiwis want euthanasia legalised.' A poll has shown more than 70% of people believe the law should be changed to allow voluntary euthanasia, but the Government isn't going to change its position. The 3 News/Reid Research poll called the question Lecretia's choice. Wellington lawyer Lecretia Seales died from a brain tumour in June just hours after her family was told the High Court had ruled against her bid to choose when she could die. http://www.3news.co.nz/nznews/poll-kiwis-want-euthanasia-legalised-2015072717#axzz3h7Os15Wa

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

A systematic review of family meeting tools in palliative and intensive care settings

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 July 2015 – The authors sought to identify tools available to aid the conduct of family meetings in palliative, hospice, and intensive care unit settings. The authors identified 16 articles containing 23 tools in 7 categories: 1) Meeting guide; 2) Meeting planner; 3) Documentation template; 4) Meeting strategies; 5) Decision aid/screener; 6) Family checklist; and, 7) Training module. They found considerable variation across tools in usage and content and a lack of tools supporting family engagement. http://ajh.sagepub.com/content/early/2015/07/23/1049909115594353.abstract

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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

Noted in Media Watch, 19 January 2015, #393 (p.9):

CRITICAL CARE MEDICINE | Online – 6 January 2015 – 'How clinicians discuss critically ill patients' preferences and values with surrogates: An empirical analysis.' In roughly a third of [the 71] ICU family conferences [recorded] for patients at high risk of death, neither clinicians nor surrogates discussed patients' preferences or values about end-of-life decision making. In less than 12% of family conferences did participants address the values of high importance to most patients, such as cognitive and physical function. Interventions are needed to ensure patients' values and preferences are elicited and integrated into end-of-life decisions in ICUs. http://journals.lww.com/ccmjournal/Abstract/publishahead/How Clinicians Discuss Critically III Patients .97364.aspx

Noted in Media Watch, 24 March 2014, #350 ('Worth Repeating,' p.16):

CRITICAL CARE MEDICINE, 2004;32(7):1484-1488. 'Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction.' The authors of this study identified family conferences in intensive care units of four Seattle [State of Washington] hospitals during which discussions about withdrawing life support were likely to occur. On average, family members spoke 29% and clinicians spoke 71% of the time. This study suggests that allowing family members more opportunity to speak during conferences may improve family satisfaction. http://journals.lww.com/ccmjournal/Abstract/2004/07000/Family_satisfaction_with_family_conferences_about.5.aspx

N.B. Additional articles on family conferences in the end-of-life care setting noted in past issues of Media Watch are listed in the weekly report of 16 September 2013, #323 (p.8).

Elder care

A diagnostic model for impending death in cancer patients: Preliminary report

CANCER | Online – 28 July 2015 – Several highly specific bedside physical signs associated with impending death within 3 days for patients with advanced cancer were recently identified. A diagnostic model for impending death based on these physical signs was developed and assessed. This model was applicable to both acute palliative care units admission and subsequent days. Upon further external validation, this model may help clinicians to formulate the diagnosis of impending death. http://onlinelibrary.wiley.com/doi/10.1002/cncr.29602/abstract

Noted in Media Watch, 16 February 2015, #397 (p.9):

CANCER | Online – 9 February 2015 – 'Bedside clinical signs associated with impending death in patients with advanced cancer: Preliminary findings of a prospective, longitudinal cohort study.' Five highly specific physical signs associated with death within 3 days among cancer patients were recently reported that may aid in the diagnosis of impending death. http://onlinelibrary.wiley.com/doi/10.1002/cncr.29048/abstract

End-of-life care in frailty

FRAILTY IN AGING. BIOLOGICAL, CLINICAL & SOCIAL IMPLICATIONS, 2015;41:151-160. The increasing prevalence of frailty within the aging population poses challenges to current models of chronic disease management and end-of-life care delivery. As frailty progresses, individuals face an increasing frequency of acute health issues requiring medical attention. The ability of health care systems to recognize and respond to acute health issues in frail patients using a holistic understanding of health and prognosis will play a central role in ensuring their effective and appropriate care, including that at the end of their lives. The authors review the history of palliative care and the elements of frailty that require the modification of current models of palliative care. In addition, tools and models for recognition of end of life in frailty and considerations for symptom management are introduced. http://www.karger.com/Article/Abstract/381232

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Noted in Media Watch, 25 November 2013, #333 (p.6):

■ U.K. (England) | BBC News – 15 November 2013 – 'GPs take on extra role for frailest patients.' The million most frail patients in England are to be identified and given a named GP to co-ordinate their care. The move has been agreed to by the British Medical Association and National Health Service England in talks over next year's GP contract. A third of emergency admissions are among the over-75s – many of which could be avoided if they received earlier and better care in the community. http://www.bbc.co.uk/news/health-24945134

Noted in Media Watch, 24 June 2013, #311 (p.11):

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS, 2013;14(6):392-397. 'Frailty consensus: A call to action.' 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... 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

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.

Care planning

Nursing futility, managing medicine: Nurses' perspectives on the transition from life-prolonging to palliative care

HEALTH | Online – 24 July 2015 – The shift from life-prolonging and palliative care can be fraught with interpersonal complexities as patients face dilemmas around mortality and the dying process. Nurses can play a central role in managing these moments, often with a focus on promoting and enhancing communication around: the meaning of palliative care, the nature of futility, and the dying process more broadly. These sites of nurse-patient communication can be highly charged and pose unique challenges to nurses including how to balance nursing perspectives versus those of other stakeholders including doctors. Here, drawing on interviews with nurses, the authors explore their accounts of communication about futility and the process of transitioning to palliative care. The interviews reveal nurses' perspectives on the following: 1) The art of conversing around futility and managing patient resistance: 2) The influence of guilt and individual biographies in shaping communication; 3) The importance of non-verbal and the informal in communication; 4) The impact of conflicting organisational expectations on nurses; and, 5) The process of learning to effectively communicate. They argue that these transitional moments articulate important, and at times problematic, aspects of contemporary nursing and nurse-medical relations. http://hea.sagepub.com/content/early/2015/07/22/1363459315595845.abstract

Of related interest:

- BIOETHICS IN FAITH & PRACTICE, 2015;1(1):13-19. 'An ethical framework for end-of-life discussions.' Society has struggled for decades to define appropriate end-of-life medical care which promotes life and does not simply prolong a person's natural death. All parties should focus on clarifying the goals of care. Patients and their families should determine what they hope to achieve restoring health, extending life, or relieving pain and suffering. Physician should provide information about the patient's prognosis and what outcomes can be accomplished by the use of specific interventions. However, physicians should not offer treatments that cannot achieve the goals of care defined by the patient and family. We still have far to go but perhaps this article has offered an ethical foundation to provide a framework for these discussions. h and practice
- ETHICS & MEDICINE: AN INTERNATIONAL JOURNAL OF BIOETHICS, 2015;31(2):109-123.
 'Autonomy vs. selflessness at the end of life.' Autonomy is the preeminent right in contemporary medical ethics. However, a closer examination of autonomy reveals that it is a flawed principle upon which to base medical decisions, particularly those at the end of life where mutually autonomous patients, physicians, and family members may come into conflict. On the one hand, autonomy may fuel a patient's desperate desire to extend his or her life by every technological means available. This exaggerates life's sanctity at the cost of its dignity. On the other hand, autonomy may prompt another patient to renounce the sanctity of life and choose "death with dignity" via physician-assisted suicide. Should the same principle be able to explain such opposite conclusions? Must medical ethics be so easily swayed by cultural preferences? http://web.a.ebscohost.com/abstract?direct=true&profile=ehost&scope=site&authtype=crawler&irnl=026668
 8X&AN=108266640&h=NiKAVAyTKjGNMCleYHNW%2fC95VhH00crMTGVvG6yCKrcFYEzNQP7F0KcBJcf QApUgAu0p43z%2bZMxqT9lOspllBA%3d%3d&crl=c&resultNs=AdminWebAuth&resultLocal=ErrCrlNotAuth&crlhashurl=login.aspx%3fdirectl%3dtrue%26profile%3dehost%26scope%3dsite%26authtype%3dcrawler%26jrnl%3d0266688X%26AN%3d108266640

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Media Watch: Palliative Care Network-e Website

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

- JOURNAL OF NURSING SCHOLARSHIP | Online 28 July 2015 'Making visible a theoryguided advance care planning intervention.' The purpose of this article is to provide details about a theory-guided advance care planning intervention, sharing the patient's illness representations to increase trust (SPIRIT), an intervention that has been shown to be efficacious for patients and their surrogates with respect to preparation for end-of-life decision making. http://onlinelibrary.wiley.com/doi/10.1111/jnu.12156/abstract
- JOURNAL OF PEDIATRIC ONCOLOGY NURSING | Online 27 July 2015 'Experiences of pediatric oncology patients and their parents at end of life: A systematic review.' The child and parent experience provides valuable information to guide how health care professionals can improve the transition to end of life and the care provided to children and families during the vulnerable period. Analysis of the evidence revealed 5 themes: 1) Symptom prevalence and symptom management; 2) Parent and child perspectives of care; 3) Patterns of care; 4) Decision making; and, 5) Parent and child outcomes of care. Guidelines for quality end-of-life care are needed. http://jpo.sagepub.com/content/early/2015/07/23/1043454215589715.abstract

N.B. Scroll down to <u>Worth Repeating</u> and 'Discussing the transition from curative cancer treatment to palliative care' (p.14), in *Palliative Medicine*.

On the ethical issues that arise when religion and treatment collide in end-of-life decision making

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2015;17(4):275-282. This article explores the ethical issues that arise when patients' and families' religious beliefs collide with clinicians' views of appropriate end-of-life decisions. The article begins with a case study drawn from clinical experience that focuses on the need for a surrogate decision maker for a deeply religious patient in the intensive care unit with life-limiting cancer. The patient's adult children, also religious, against the health care team's clinical advice, want all life-extending measures taken as they await a divine miracle. The conflict between the family and health care team points to the 1) ethical issues of patients' and families' status of vulnerability and the health care team's necessary moral response to this status; 2) moral obligation of the health care team to show their trustworthiness to the family by showing the family the team's competence, honesty, and reliability; and, 3) moral obligations of the health care team to provide the patient and family spiritual support. http://journals.lww.com/jhpn/Abstract/2015/08000/On the Ethical Issues That Arise When Religion and.3.aspx

Noted in Media Watch, 19 January 2015, #393 (p.15):

JOURNAL OF RELIGION & HEALTH | Online – 10 January 2015 – 'Religious, ethical and legal considerations in end-of-life issues: Fundamental requisites for medical decision making.' A patient's religious affiliation constitutes a key component in medical decision making. This is particularly pertinent in issues involving end-of-life decisions such as withdrawing and withholding treatment, medical futility, nutritional feeding, and do-not-resuscitate orders. http://link.springer.com/article/10.1007/s10943-014-9995-z

N.B. Listed in this issue of Media Watch are selected articles on religion and end-of-life decision making noted in past issues of the weekly report.

Noted in Media Watch, 13 June 2011, #205 (p.8):

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 6 June 2011 – 'Approaching patients and family members who hope for a miracle.' An evidence-based approach is provided for the clinician by breaking this complex clinical problem into a series of more focused clinical questions and subsequently answering them through a critical appraisal of the existing medical literature. http://www.jpsmjournal.com/article/S0885-3924(11)00243-0/abstract

French guidelines on non-university continuing education in palliative care

MÉDECINE PALLIATIVE | Online – 29 July 2015 – Good practice recommendations for continuing education in palliative care were prepared according to the method of formalized expert consensus under the auspices of the French Society for Palliative Care and French Health Authority. These recommendations concern the continuing education of practitioners and care providers in hospitals as well as in private practice. It is essential to disseminate them widely to improve the quality of the training in palliative approach and in the care of patients needing palliative care and at the end-of-life. http://www.sciencedirect.com/science/article/pii/S1636652215000926

N.B. French language article.

Coverage and development of specialist palliative care services across the World Health Organization European Region (2005-2012): Results from a European Association for Palliative Care Task Force survey of 53 countries

PALLIATIVE MEDICINE | Online – 31 July 2015 – Of 53 countries, 46 provided data. Europe developed significant home care team, inpatient palliative care service, and hospital support team in 2005-2012. The improvement was statistically significant for Western European countries, but not for Central and Eastern countries. Significant development in at least a type of service has been seen in 21 of 46 countries. The estimations of 2012 coverage for inpatient palliative care service, home care team and hospital support team are 62%, 52% and 31% for Western European and 20%, 14% and 3% for Central and Eastern, respectively. Although there has been a positive development in overall palliative care coverage in Europe between 2005 and 2012, the services available in most countries are still insufficient to meet the palliative care needs of the population. http://pmj.sagepub.com/content/early/2015/07/31/0269216315598671.full.pdf+html

Implementation of National Comprehensive Cancer Network Palliative Care Guidelines by member institutions

SUPPORTIVE CARE IN CANCER | Online - 31 July 2015 - Increasingly, evidence suggests the integration of palliative care (PC) with standard oncologic care can yield substantial benefits. As part of an effort to improve the PC of cancer patients, the [Washington-based] National Comprehensive Cancer Network (NCCN) has developed clinical practice guidelines for PC that promote access to quality, evidence-based PC. This study sought to characterize current implementation of the guidelines by NCCN member institutions. Institutional representatives appointed to the NCCN Palliative Care Guidelines Panel were asked to complete an online survey in the spring of 2014. The survey focused on availability of PC services, screening and referral practices for PC, PC education, and quality improvement programs. The survey was completed by representatives from 21 of 25 NCCN member institutions (84 %). A majority routinely provides PC services via interdisciplinary teams; 52 % routinely inform patients of the availability, elements, and benefits of PC. The guidelines are most often used to guide clinical practice; only 10 % reported using the guidelines to formally screen for PC needs and/or make referrals to PC specialists. Among the 62 % of institutions that screen any patients using any available criteria, when a patient screens positive for PC needs, a referral to a PC specialist is made less than half the time. Implementation of PC guidelines is incomplete and various aspects of the guidelines, such as the recommendation to screen all patients for PC needs, are applied inconsistently. Despite this, most institutions provide PC services in a manner consistent with the guidelines. Greater implementation of the guidelines' recommendations is needed. http://link.springer.com/article/10.1007/s00520-015-2862-v

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

Of related interest:

- PALLIATIVE MEDICINE | Online 29 July 2015 'Introducing a model incorporating early integration of specialist palliative care: A qualitative research study of staff's perspectives.' While early symptom management was considered valuable, nurses particularly found additional skill expectations challenging, and perceived patients' acute care needs as detracting from emotional and end-of-life care demands. Staff views varied on whether they regarded the new model's faster-paced work-life as consistent with fundamental palliative care principles. http://pmj.sagepub.com/content/early/2015/07/29/0269216315598069.abstract
- IMPLEMENTATION SCIENCE | Online 26 July 2015 'Implementation of improvement strategies in palliative care: An integrative review.' Although a growing number of new insights and best practices in palliative care have been published, they are often not implemented in daily practice. The aim of this review is to provide an overview of implementation strategies that have been used to improve the organisation of palliative care. This review is one of the first to provide an overview of the available literature in relation to strategies used to improve the organisation of palliative care. http://www.implementationscience.com/content/10/1/103

Media Watch: Online

International

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

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

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

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

Asia

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

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

Australia

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

Canada

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BMJ OPEN | Online 27 July 2015 'Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: A retrospective, descriptive study.' Depression and personality disorders are the most common diagnoses in psychiatric patients requesting euthanasia, with Asperger syndrome representing a neglected disease burden. Further research is needed, especially prospective quantitative and qualitative studies, to obtain a better understanding of patients with psychiatric disorders who request euthanasia due to unbearable psychological suffering. http://press.psprings.co.uk/Open/july/bmjopen007454.pdf
- THE GERONTOLOGIST | Online − 28 July 2015 − 'Older people's discourses about euthanasia and assisted suicide...' The [study] participants presented a "confused and conflicted" discourse, expressing the view that euthanasia and assisted suicide (EU/AS) is a family affair, whilst also articulating a strong sense of self-determination. Although a discourse of the medicalization of dying through medical control and surveillance was endorsed, an alternative discourse of "dying outside the medical gaze" emerged. Participants, who were in favor of EU/AS, felt "voiceless," as apparent double standards were applied in the debate, and powerful others, for example, physicians and politicians, seemed reluctant to engage. Within an "aged death" discourse, the anticipated dependency on poor care from (professional) others, made participants consider EU/AS as ways of avoiding this stage of life and the associated loss of dignity. http://gerontologist.oxfordjournals.org/content/early/2015/07/28/geront.gnv102.abstract

Worth Repeating

"Would you like to talk about your future treatment options?"

Discussing the transition from curative cancer treatment to palliative care

PALLIATIVE MEDICINE, 2006;20(4):397-406. There comes a time when actively pursuing aggressive curative treatment may do more harm than good. The cessation of curative treatment is often viewed as a distinct event; however, current practice guidelines suggest that a palliative approach should be gradually adopted as the disease progresses. The challenge is how to facilitate a sensitive transition from curative to palliative care. On the basis of an extensive literature review, recommended steps for facilitating this transition have been outlined. The [authors'] recommendations cover: 1) The timing of the discussion; 2) Preparing for this discussion; 3) The environment and circumstances of the consultation; 4) Initiating the discussion; 5) Identifying the information to be provided; 6) Responding to the person's emotional reaction; 7) Introducing palliative care services; 8) Continuity of care; 9) Family concerns; 10) Cultural and linguistic diversity; and, 11) Concluding the discussion. These steps were based on the best available evidence. http://pmi.sagepub.com/content/20/4/397.short

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