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 Specialist Publications and 'Knowledge and skills needed by informal carers to look after terminally ill patients at home' (p.9), in End of Life Journal.

U.S.A.

Hospice statistics: The United States of dying

IDAHO | The Blue Review (Boise State University) - 31 July 2014 - Hospice care has risen dramatically in the last decade, quadrupling in size according to a recent Huffington Post investigation. The authors [of this article] break down the size and cost of the hospice industry by state. Alaska has a high number of hospice facilities (per capita), but not as many patients, whereas lowa has the largest number of per capita hospice beneficiaries. Idaho, a large, rural state like Alaska, also has more facilities than average and about 4.4 hospice patients per 100,000 people. https://thebluereview.org/hospice-statistics-united-statesdying/?utm_source=rss&utm_medium=rss&utm_campaign=hospice-statistics-united-states-dying

'How dying became a multibillion-dollar industry,' The Huffington Post, 19 June 2014. [Noted in Media Watch, 23 June 2014, #363 (p.2)] http://projects.huffingtonpost.com/hospice-inc

Of related interest:

NATIONAL PUBLIC RADIO | Online - 29 July 2014 - 'Getting hospice care shouldn't have to mean giving up.' It's a painful dilemma for seriously ill Medicare patients: In order to receive the extra support, counseling and care provided by the program's hospice benefit they have to agree to stop receiving curative treatment for their disease. Faced with that stark either-or choice, many forgo hospice care until the last days of their lives. Now an experimental project, set to enroll 30,000 people over the next few years, will allow some hospice-eligible Medicare patients get treatment for the disease and hospice care at the same time. http://www.npr.org/blogs/health/2014/07/28/336120433/getting-hospice-care-shouldnt-have-tomean-giving-up

Noted in Media Watch, 19 May 2014, #358 (p.3):

REUTERS | Online - 14 May 2014 - 'Under new Medicare model, members may not have to choose between treatment and hospice.' A new program from the Centers for Medicare & Medicaid Services may remove a barrier that makes patients hesitate to opt for hospice care near the end of life. http://www.reuters.com/article/2014/05/14/us-curativehospice-medicare-idUSKBN0DU1P220140514

- MCKNIGHTS | Online 31 July 2014 'Medicare rates could be adjusted for start and end of hospice care episodes, Centers for Medicare & Medicaid Services report suggests.' Medicare payments could be adjusted to reflect how hospice services tend to be more intensive at the beginning and end, according to findings recently published by the Centers for Medicare & Medicaid Services Office of Information Products & Data Analytics. http://www.mcknights.com/medicare-rates-could-be-adjusted-for-start-and-end-of-hospice-care-episodes-cms-report-suggests/article/363666/
 - 'Medicare's hospice benefit: Analysis of utilization and resource use,' Medicare & Medicaid Research Review, 2014;4(2):e1-14. http://www.cms.gov/mmrr/Downloads/MMRR2014_004_02_b03.pdf

How will you die?

NATIONAL PUBLIC RADIO | Online - 31 July 2014 – When you dig into global statistics, two interesting facts pop out. The first is that, from a scientific perspective, we all pretty much die the same way: lack of blood to the brain. But how we get to that last stage varies quite a bit. And in a global sense, it varies depending on where you live and how much money you make. The World Bank says there are 213 countries... 1 It divides them into three groups based on average income per person: high-, middle- and low-income countries. Two of these groups probably make less money than you'd think. Here's the rough breakdown, in average dollars earned per person each vear: High income, \$39,312; middle income, \$4,721; low income, \$664. Most people in the world, about 5 billion of them, fall somewhere in the middle-income category. Then there are about a billion people in high-income countries and a billion in low-income countries. So if you live in a high-income country, the top three ways to die are heart disease, stroke and lung diseases, including lung cancer, the WHO says.2 But if you live in one of the world's poorest countries, the top killers are lower respiratory infections, HIV/AIDS and diarrhea. In rich countries, 7 out of 10 people make it past their 70th birthday. In poor countries, that percentage drops to 2 out of 10 people. In fact, in the 34 poorest countries in the world, only 6 out of 10 people make it past their 15th birthday. http://www.npr.org/blogs/goatsandsoda/2014/07/31/336369873/how-will-you-die

Specialist Publications

'25 million older Americans have experienced unwanted or excessive medical treatment' (p.10), in *Health News Digest.*

'Two steps forward, one step back: Changes in palliative care consultation services in California hospitals from 2007 to 2011' (p.11), in *Journal of Palliative Medicine*.

'How should a catholic hospice respond to patients who choose to voluntarily stop eating and drinking in order to hasten death?' (p.12), in *The Linacre Quarterly*.

- 1. 'Countries and economies,' The World Bank: http://data.worldbank.org/country
- 'The top 10 causes of death,' World Health Organization: http://www.who.int/mediacentre/factsheets/fs310/en/index1.html

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

State scorecard

State ranks high on long-term elder care, but caregivers' needs not met

CONNECTICUT | The Courant (Hartford) -30 July 2014 - Connecticut ... ranks 12th overall among all 50 states, and the District of Columbia, in meeting 26 indicators across five key dimensions of care.1 The state scored high in offering choice of setting and provider, quality of life and quality of care. And while it ranks high for access to care, it needs to substantially improve affordability. The state fares poorly in care transitions (39th) - the process of shifting care from one setting to another - and in support for family caregivers (30th). Minnesota ranked highest across all dimensions, while Kentucky was 51st across the five benchmarks. Rhode Island was 38th overall and Massachusetts was 18th. Affordability of long-term care services - especially for the middle class, who don't qualify for Medicaid - remains a huge obstacle. The cost of nursing homes is well beyond what an average consumer can afford according to the new ratings. The median annual private pay cost for a nursing home as a percentage of median household income for those age 65 and older was a whopping 359% in Connecticut. In comparison, the national median rate is 234% and in the state with the lowest rate, Oklahoma, it's 168% of median income. http://www.courant.com/health/connecticut/hc-health-caregivers-20140730,0,2867639.story

Extract from 2014 State Scorecard report

When there are excessive transitions between hospitals, nursing homes, and home and community-based settings, quality of care suffers, as does quality of life. It creates stress for family caregivers and often violates the preferences of people at the end of life who would prefer to die at home.

 '2014 State Scorecard on Long-Term Services and Supports for Older Adults and People with Physical Disabilities,' published by the AARP Public Policy Institute, the Commonwealth Fund and the SCAN Foundation, June 2014. [Noted in Media Watch, 23 June 2014, #363 (p.3)] http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2014/raising-expectations-2014-AARP-ppi-ltc.pdf

Of related interest:

THE NEW YORK TIMES | Online – 28 July 2014 – 'Nursing home unthinkable? Be prepared in case it's inevitable.' Nobody looks forward to spending their final years in a nursing home, yet 1.4 million Americans are living in this often-feared institutional setting. You may not want to place a loved one in a nursing home for more than a short-term recovery – but never promise an aging relative that it won't happen. Nursing homes generally have had a bad reputation as smelly, indifferent places where people go to die. But "there are some homes that are better than being at home" [and] "there are many more good facilities than bad ones." http://well.blogs.nytimes.com/2014/07/28/nursing-home-unthinkable-be-prepared-in-case-its-inevitable/?partner=rss&emc=rss

N.B. See 'Survey: Most Americans underestimate nursing-home costs,' MoneyRates, June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.5)] http://www.money-rates.com/research-center/americans-underestimate-nursing-home-costs.htm

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.16.

Tools for planning end-of-life care are varied, untested: Study

REUTERS | Online – 29 July 2014 – Many tools exist to help introduce people to the subject of advanced care planning, but they vary widely in what they offer and how accessible they are, according to a new research review. The authors found the tools ... most readily available often have not been vetted by formal studies, and the ones that have are often not accessible to the public or are specific to certain diseases. Less than half of severely or terminally ill patients have an advance directive in their medical record, according to the authors, and past research has found doctors are only correct 65% of the time in predicting what intensive care a patient would want. Some patients prioritize living longer, whereas others may not wish to be kept alive when meaningful recovery or a particular quality of life is no longer possible, write the authors. One common "advanced directive" is a do not resuscitate order, but the directives can be much more nuanced than that, taking into account religion, spirituality and philosophical outlook, they note. http://www.reuters.com/article/2014/07/29/us-advance-directives-health-idUSKBN0FY1VV20140729

'Decision aids for advance care planning: An overview of the state of the science,' Annals of Internal Medicine, 29 July 2014. The 16 published studies testing decision aids as interventions for adult advance care planning found that most are proprietary or not publicly available. Some are constructed for the general population, whereas others address disease-specific conditions that have more predictable end-of-life scenarios and, therefore, more discrete choices. http://annals.org/article.aspx?articleid=1891307

Assisted (or facilitated) death

Representative sample of recent news media coverage:

NEW JERSEY | 101.5 News (Trenton) – 28 July 2014 – 'Poll: 51% support doctor-assisted suicide in New Jersey.' "Fifty-one percent say they think policymakers should support the legislation that gives someone with fewer than six months to live the option to end his or her own life with the help of a doctor," said Krista Jenkins, director of PublicMind and professor of political science at Fairleigh Dickinson University. "A little more than a third, or 38%, are opposed to the legislation." Aid in Dying for the Terminally III Act would require terminally ill patients with six months or less to live, to verbally ask for a prescription from their doctor. That would be followed by a second verbal request at least 15 days later, and one written request signed by two witnesses. The doctor would have to offer the patient a chance to change their mind, and another physician would have to certify the original diagnosis and reaffirm the patient is of sound mind. The patient would have to self-administer the drugs. The bill was passed by the Assembly Health & Senior Services Committee in June. http://nj1015.com/poll-51-percent-support-doctor-assisted-suicide-in-nj/

Noted in Media Watch, 7 July 2014, #365 (p.2):

■ NEW JERSEY | The Star-Ledger (Newark) – 28 June 2014 – 'Assembly wise to wait on assisted-suicide bill: Editorial.' Assemblyman John Burzichelli was smart to pull his assisted-suicide bill. A defeat would give too much credence to critics who say the law could put the state's elderly and disabled in mortal danger. The bill is meant to give terminally ill patients the choice to end their lives with a lethal dose of physician-prescribed drugs.http://www.nj.com/opinion/index.ssf/2014/06/assembly wise to wait on assisted suicide bill editorial.html

Media Watch posted on Palliative Care Network-e Website

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

International

Palliative care and Māori from a health literacy perspective

NEW ZEALAND | Ministry of Health – 1 August 2014 – Health literacy refers to the degree people can access and understand health information to make informed and appropriate health decisions. There is a limited amount of research into the Māori experience of palliative care and issues of access. The report focuses on gaining a better understanding of ways to increase access to, and the quality of, palliative care services for Māori patients and their whānau [extended family] by strengthening health literacy. It summarises the key points from two health literacy and palliative care research reports. The report also provides recommendations for actions to enhance Māori health literacy and access to palliative care. http://www.health.govt.nz/publication/palliative-care-and-maori-health-literacy-perspective

- 'Māori health literacy and communication in palliative care: Kaumātua-led models,' 2014. http://www.health.govt.nz/system/files/documents/publications/maori-health-literacy-communication-in-palliative-care-kaumatua-led-models-aug14.pdf
- 'Health literacy in palliative care,' 2014. https://cdn.auckland.ac.nz/assets/fmhs/faculty/ABOUT/newsandevents/docs/Health-literacy-in%20palliative-care-report.pdf

N.B. Articles on Māori beliefs and practices, and end-of-life care, are noted in Media Watch, 16 June 2014, #362 (p.8) and 17 March 2014, #349 (p.9).

French families challenge doctors on wrenching end-of-life decisions

FRANCE | The New York Times (Paris) - 31 July 2014 - Doctors in France have long held what, by American standards, might seem unthinkable discretion to make end-oflife choices for people in their care. For patients unable to communicate, such decisions fall legally to the physician, who may withdraw treatment or administer care that will end a patient's life so long as the stated intent is to relieve that patient's suffering, and not to kill. The opinions of family members and fellow doctors must be heard, the law states, but by no means obeyed. That physicians wield such expansive powers is a peculiarity born of France's paternalistic bent, of a culture of deference to hierarchy and expertise, doctors and social scientists say. Never have fears of "death panels" become a matter of public debate, as they have in the U.S. As the population ages, however, and as drawn-out hospital deaths become more the norm, patients and families increasingly say they wish to be more closely involved in end-of-life decisions. And the French doctor's role as final arbiter of life and death is increasingly being challenged. A bipartisan proposal for new end-of-life legislation is to be presented to President François Hollande in the coming months. http://www.nytimes.com/2014/08/01/world/e urope/french-families-challenge-doctors-on-wrenching-end-of-life-decisions-medicalized-hospital-deaths.html?ref=health& r=0

French hospital to open wine bar for patients as doctor defends the "right to have fun"

FRANCE | The Independent (U.K.) - 31 July 2014 - A hospital may seem like the most unlikely place to find a wine bar but "medically supervised" tipples will soon be allowed for patients in France. Fine wines, champagne and whisky will be among the choices at the unusual establishment being opened in September. The bar will be in the palliative care centre at Clermont-Ferrand University Hospital in Puyde-Dôme, central France, which offers comfort for people with chronic and terminal illnesses. Dr. Virginie Guastella, the centre's manager, said she was defending "the right to have fun" and hopes the idea will catch on in other hospitals to brighten up the lives of patients and their families. http://www.independent.co.uk/life-style/healthand-families/health-news/french-hospital-to-openwine-bar-for-patients-as-doctor-defends-the-rightto-have-fun-9641920.html

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

Leicester, Leicestershire and Rutland end-of-life care "unacceptable"

U.K. (England) | BBC News - 31 July 2014 -One in five patients who died in Leicestershire and Rutland received "unacceptable levels" of end-of-life care, a review has found. The report looking at the cases of 381 patients found some were resuscitated when it was not in their best interests. Some patients were brought into hospitals despite saying that they wanted to die at home. National Health Service (NHS) bosses have apologised to families for "letting people down." The internal review focused on care patients received between March 2012 and June 2013, including from hospitals, GPs, and social services. A total of 89 patients about 23% of the sample - received "unacceptable" care [see sidebar right]. The report's authors Ron Hsu and Lucy Douglas-Pannett said: "There was evidence of fractured care, dysfunctional processes and lack of joined-up thinking throughout the NHS in Leicester, Leicestershire and Rutland." http://www.bbc.com/news/uk-englandleicestershire-28580508

Extract from the report of internal review

Confusion over "do not resuscitate" orders, which meant patients were resuscitated when it would have been "in their best interests" to have had end-of-life care and comfort.

Poor communication between parts of the health system and within hospitals led to delays in diagnosis and some patients were "not recognised as being at the end of life.

Patients who had expressed a preference to die at home were brought into hospital.

Specialist Publications

What works in "real life" to facilitate home deaths and fewer hospital admissions for those at end of life? Results from a realist evaluation of new palliative care services in two English counties' (p.9), in *BMC Palliative Care*.

Of related interest:

U.K. (England) | Help the Hospices – 29 July 2014 – The Commissioning of Hospice Care in England 2014/15 A survey found a significant proportion of hospices are experiencing frozen or reduced funding, increasing complexity of commissioning arrangements and an absence of proportionality in the contractual arrangements being required by many NHS commissioners. http://www.helpthehospices.org.uk/EasySiteWeb/EasySite/getresource.axd?AssetID=141290

Dutch model offers new approach to home care

THE NETHERLANDS | Australian Ageing Agenda – 30 July 2014 – Not-for-profit organisation Buurtzorg Nederland, founded and developed by community nurses, is transforming home care in The Netherlands and is quickly garnering attention worldwide, including in Australia. Since its development in 2006, the Buurtzorg or "neighbourhood care" model has attracted the interest of more than 25 countries, including the National Health Service in England. Sweden, Japan and the U.S. state of Minnesota have already begun introducing Buurtzorg nurse-led teams in their jurisdictions. http://www.australianageingagenda.com.au/2014/07/30/dutch-model-offers-alternative-approach-home-care/

Of related interest:

U.K. | The Daily Telegraph – 28 July 2014 – 'Give people a legal right to die at home, says former Labour health minister.' Lord Warner, a former Labour health minister, proposed legislation which would allow people to formally register a preference on where they would die. http://www.telegraph.co.uk/news/politics/10996362/Give-people-a-legal-right-to-die-at-home-says-former-Labour-health-minister.html

U.K. (England) | The Guardian – 28 July 2014 – 'Are 15-minute homecare visits always bad?' Local authorities often face criticism for the regimented way they purchase care and particularly for the hourly rates they offer. Interested observers will talk about the need to purchase care around outcomes, rather than the seemingly outdated method of paying by the hour, half hour or 15 minutes. In reality this is a bit of a holy grail as very few local authorities have mastered the art of outcome-based commissioning. http://www.theguardian.com/social-care-network/2014/jul/28/are-15-minute-homecare-always-bad

Parents of a nine-month-old terminally ill baby girl want to bring her home for "miracle cure" – court

IRELAND | *The Independent* (Dublin) – 29 July 2014 – The parents of a nine month old terminally ill baby girl at the centre of a High Court case over whether or not a hospital should resuscitate her want to bring her home. She has a rare disorder in which cells affecting every part of her body run out of energy and sufferers in infancy usually die within 12 months from heart failure, the court heard. There is no cure. The Health Services Executive applied to the High Court to allow the hospital she is being treated in not to resuscitate her should she have one of these "cardio pulmonary events." It is claimed administering cardiopulmonary resuscitation (CPR) and ventilation was not in her best interests as it would be too invasive, causes great distress and could fracture the baby's ribs. The parents ... had opposed the non-resuscitation application. After hearing evidence and reports from a number of doctors, president of the High Court, Mr. Justice Nicholas Kearns, said he was reserving his decision on the matter which he said was "of great importance to everybody." http://www.independent.ie/irish-news/courts/parents-of-a-ninemonthold-terminally-ill-baby-girl-want-to-bring-her-home-for-miracle-cure-court-30468402.html

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.' A clinical problem may arise when caring for patients ... who prefer continued aggressive care based on the belief that a miracle will occur, despite a clinician's belief that further medical treatment is unlikely to have any meaningful benefit. 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

End-of-life care in Southeast Asia

National University Hospital starts palliative care service in emergency department

SINGAPORE | The Straits Times – 28 July 2014 – The National University Hospital [NUH] is starting a dedicated palliative care service in its emergency department (ED) to relieve patients' suffering. Doctors see the need as more elderly have died in the ED in the past two years. "As our population ages, patients with advanced chronic illness and crisis events such as severe pneumonia or heart attack, are likely to increase," said Associate Consultant for Emergency Medicine Rakhee Yash Pal at NUH. "The default mode in emergency medicine is maximum resuscitation, but not every patient might want or benefit from that." NUH is also be-

lieved to be the first hospital to start a palliative service in its ED. Currently, patients and their family members might need to wait several hours to see a palliative specialist, especially if an emergency happens at night. http://www.straitstimes.com/news/singapore/health/story/national-university-hospital-starts-palliative-care-service-emergency-de

Specialist Publications

'Role of acute oncology in the transition to palliative care' (p.10), in *End of Life Journal*.

Selected articles on end-of-life care in the emergency department noted in past issues of Media Watch:

- INTERNAL MEDICINE JOURNAL | Online 16 February 2014 'Care of the dying cancer patient in the emergency department: Findings from a national survey of Australian emergency department clinicians.' Although 83.8% [of survey respondents] found caring for the dying a reasonable demand on their role as clinician, 83.8% also agreed that the emergency department is not the right place to die. [Noted in Media Watch, 24 February 2014, #346 (p.11)] https://onlinelibrary.wiley.com/doi/10.1111/imj.12379/abstract
- EMERGENCY MEDICINE AUSTRALASIA | Online 25 July 2013 'Do patients die well in your emergency department?' Only 49% of survey respondents believed the emergency department provided good palliative care, and 80% were unaware of international gold standard palliative care protocols. Most had access to hospital-based palliative care specialists (77%); however, only 19% used them. [Noted in Media Watch, 5 August 2013, #317 (p.7)] http://onlinelibrary.wiley.com/doi/10.1111/1742-6723.12099/abstract;jsessionid=BF3EB5C23715B5BCDC40C9E6BBA8E026.d04t04?deniedAccessCustomisedMessage=&userlsAuthenticated=false
- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE | Online 23 May 2012 'Why do palliative care patients present to the emergency department? Avoidable or unavoidable?' With an understanding of why patients present, interventions to avoid these presentations close to the end of life may be possible. A comprehensive, coordinated approach across community and acute services may help to ensure patients are not sent to the emergency department inappropriately. [Noted in Media Watch, 4 June 2012, #256 (p.7)] http://ajh.sagepub.com/content/early/2012/05/18/1049909112447285.abstract

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

The nature and importance of quality of therapeutic relationships in the delivery of palliative care to people with intellectual disabilities

BMJ SUPPORTIVE PALLIATIVE CARE | Online – 29 July 2014 – Staff (i.e., study participants) valued their relationships with service users, and felt that the quality of their relationship affected its therapeutic potential. Participants described factors fundamental to the development of quality relationships. Palliative care and intellectual disability staff commented on the importance of trust, of continuity of relationship, and of knowing the individual. However, palliative care staff admitted to difficulties in these areas when providing care to people with intellectual disabilities. It appeared that quality of care was affected in situations where staff failed to form authentic relationships. http://spcare.bmj.com/content/early/2014/07/29/bmjspcare-2013-000619.abstract

Communication of humor during bereavement: Intrapersonal and interpersonal emotion management strategies

COMMUNICATION QUARTERLY, 2014;62(4):436-454. This study examined how the communication of humor plays a role in managing emotions and physical symptoms related to bereavement. Results ... [of this study] ... reveal that pre-dispositional humor production is associated with greater coping efficacy, reduced incidence of negative physical and emotional symptoms, and, overall, aids individuals in functioning during grief. Differential patterns of humor pertaining to the specific death context (appropriateness of humor/avoiding censure) predicted poorer coping and negative symptoms. There were also important male-female differences with men scoring higher on humor enactment, coping efficacy, and lower on negative feelings and symptoms compared to women. http://www.tandfonline.com/doi/abs/10.1080/01463373.2014.922487#.U9ew--NdX8k

Knowledge and skills needed by informal carers to look after terminally ill patients at home

END OF LIFE JOURNAL, 2014;4(2). Carers need specific knowledge and skills at different points over the duration of their role. Ultimately, carers need to know they are doing the right thing and that appropriate help and guidance will be available if they need it. Adequate support should result in the experience of caring for a loved one with palliative care needs at home being improved. Two main themes emerged in this study, with associated sub-themes: 1) knowing the right thing to do (sub-themes: need for knowledge and practical skills; managing symptoms and administering medications; knowing what is best for the person); and, 2) personal experiences of caring (sub-themes: impact of caring on health; the need to accept help; and experiencing a sense of satisfaction). Participants suggested carers require adequate preparation for the caring role...http://endoflifejournal.stchristophers.or g.uk/research/knowledge-and-skills-neededby-informal-carers-to-look-after-terminally-illpatients-at-home

What works in "real life" to facilitate home deaths and fewer hospital admissions for those at end of life? Results from a realist evaluation of new palliative care services in two English counties

BMC PALLIATIVE CARE | Online - 30 July 2014 - Factors contributing to success included services staffed with experienced palliative care professionals with dedicated (and sufficient) time for difficult conversations with family carers, patients and/or clinical colleagues about death and the practicalities of caring for the dying. Using their ... knowledge of the local healthcare system, they accessed community resources to support homecare and delivered excellent services. This engendered confidence and reassurance for staff, family carers and patients, possibly contributing to less hospital admissions and accident and emergency attendances and more home deaths. http://www.biomedcentral.com/content/pdf/1472-684X-13-37.pdf

Selected articles on home palliative care noted in past issues of Media Watch:

- PALLIATIVE & SUPPORTIVE CARE | Online 9 June 2014 'Preparing for family caregiving in specialized palliative home care: An ongoing process.' Study participants described their experience of preparing for caregiving as an ongoing process, rather than something done in advance. The process was illustrated through three sub-processes: "awaring" (realizing the seriousness of the situation), "adjusting" (managing a challenging situation), and "anticipating" (planning for the inevitable loss). [Noted in Media Watch, 16 June 2014, #362 (p.12)] http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9279476&fulltextType=RA&fileId=S1478951514000558
- BMC PALLIATIVE CARE | Online 17 April 2014 "It's alright to ask for help": Findings from a qualitative study exploring the information and support needs of family carers at the end of life.' Family carers experience multiple needs for information and education, but meeting these needs remains a challenge. Three domains could underpin this type of intervention: 1) developing knowledge and competence; 2) facilitating preparedness; and, 3) supporting role recognition and confidence building. [Noted in Media Watch, 21 April 2014, #354 (p.9)] http://www.biomedcentral.com/content/pdf/1472-684X-13-22.pdf
- JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2004;291(4):483-491. "They don't know what they don't know": Supporting family caregivers at the end of life.' The amorphous relationship between physicians and the families of patients at the end of life presents both challenges and opportunities for which physicians may be unprepared. [Noted in Media Watch, 26 July 2010, #159 (p.11, under "Worth Repeating")] https://jama.ama-assn.org/cgi/content/abstract/291/4/483?maxtoshow=&hits=10&RESULTFORMAT=&fulltext=foregiveness+at+the+end+opf+life&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT

Role of acute oncology in the transition to palliative care

END OF LIFE JOURNAL, 2014;4(2). Patients with cancer may attend hospital emergency departments as a result of complications of their disease process and treatment... In addition, patients with undiagnosed cancer can also present at emergency departments when they become symptomatic. The acute care culture within hospitals means that patients with cancer who are approaching the end of life are sometimes subjected to futile interventions and treatment. Acute oncology is a relatively new hospital service that aims to enhance the experience and outcomes of patients who present as emergency admissions as a result of complications of cancer and its treatment or for whom a cancer diagnosis is suspected but has not been confirmed. It brings together the expertise of clinicians working in emergency care, acute medicine and oncology. http://endoflifejournal.stchristophers.org.uk/professional-issues/role-of-acute-oncology-in-the-transition-to-palliative-care

25 million older Americans have experienced unwanted or excessive medical treatment

HEALTH NEWS DIGEST | Online – 29 July 2014 – A new poll shows nearly one out of four older Americans say that either they or a family member have experienced excessive or unwanted medical treatment, the equivalent of about 25 million people. The survey reveals older Americans strongly support holding doctors accountable when they fail to honor patients' end-of-life healthcare wishes. Six out of 10 of those polled support reimbursing doctors for end-of-life consultations; nearly two-thirds support withholding payment to healthcare providers who fail to honor their end-of-life medical wishes. Clear super majorities of the survey respondents would discuss (93%) or write down (90%) their advance directive, or change (91%) or speak (84%) to their own doctors. Nineteen out of 20 poll respondents said it is important for healthcare providers to respect their end-of-life medical wishes. Most are very confident their families (73%) and doctors (63%) will honor their medical wishes. http://www.healthnewsdigest.com/news/National_30/25-Million-Older-Americans-Have-Experienced-Unwanted-or-Excessive-Medical-Treatment.shtml

 'Unwanted Medical Treatment Survey,' Purple Insights, February 2014 https://www.compassionandchoices.org/userfiles/UMT-survey-feb-2014.pdf

Palliative and end-of-life care in prisons: A content analysis of the literature

INTERNATIONAL JOURNAL OF PRISONER HEALTH, 2014;10(3). The growing numbers of terminally ill and dying in prison has high economic and moral costs as global correctional systems and the society at large. However, to date little known about the extent to which palliative and end-of-life care is infused within global prison health care systems. The purpose of this review is to fill a gap in the literature by reviewing and critically appraising the methods and major findings of the international peer-reviewed literature on palliative and end-of-life care in prison, identify the common elements of promising palliative and end-of-life services in prison, and what factors facilitated or create barrier to implementation. It provides a foundation on which to build on about what is known thus far about the human right to health, especially parole policy reform and infusing palliative and end-of-life care for the terminally ill and dying in prisons. This information can be used to develop or improve a new generation research, practice, policy, and advocacy efforts for that target terminally ill and dying in prison and their families and communities. http://www.emeraldinsight.com/journals.htm?issn=1744-9200&volume=10&issue=3&articleid=17117134&show=abstract

N.B. The provision and delivery of end-of-life care in the prison system have been highlighted in Media Watch on a regular basis. A compilation of articles, reports, etc., on this public health issue noted in the weekly report in recent years is available online at the Palliative Care Community Network website: http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons.

Two steps forward, one step back: Changes in palliative care consultation services in California hospitals from 2007 to 2011

JOURNAL OF PALLIATIVE MEDICINE | Online – 1 August 2014 – The number of palliative care consultation services is growing, yet little is known about how program characteristics change over time. There were 41 new palliative care programs [in California] since 2007; 17 programs closed between 2007 and 2011. Hospital characteristics associated with the closure of a palliative care program included a hospital size of 1-149 beds versus 150 or more, for-profit status, and having no system affiliation. The prevalence of palliative care consultation services was 33% in 2007 and 37% in 2011. At both time periods nearly all palliative care consultation services (98%) were available onsite during weekday business hours and only half were available at other times. There was an increase in nurse/physician full-time equivalent ... but fewer teams reported having social workers ... and chaplains ... in 2011. Over half of the palliative care consultation services reported seeing less than 50% of patients who would benefit from a consultation ... yet most also reported struggling to cope with patient volume... Fewer than half of hospitals in California offer a palliative care program and many close over time. Making palliative care consultation services a condition of participation by insurers could make hospital palliative care consultation services universal. Mechanisms need to be established to improve staffing levels, maintain the interdisciplinary nature of palliative care consultation services, and accommodate demand for services. http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0105

Palliative care for severely affected patients with multiple sclerosis: When and why? Results of a Delphi Survey of health care professionals

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 July 2014 – Results clearly identified specific areas in which palliative care will likely prove to be a valuable asset in the treatment course of multiple sclerosis. This information should serve clinicians, indicating when to consider palliative care services and help further reduce or eliminate uncertainty about how palliative care can be integrated in the course of MS. http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0667

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

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

Enhancing the empathic connection: Using action methods to understand conflicts in end-of-life care

JOURNAL OF PATIENT EXPERIENCE, 2014;1(1):14-21. This paper illustrates how action methods used psycho-dramatically can reveal the personal and interpersonal dynamics often seen in complex patient and family encounters. These insights are particularly important because, in Southern European countries such as Italy, openness in discussing bad news is less common, and the paternalistic approach of protecting the patient is very strong. Some available data suggest that the climate is changing toward providing essential medical information to patients and families, but unpleasant communication such as disclosure of diagnosis and prognosis is often concealed. Finally, the conclusions drawn from the evaluation of this project must be interpreted cautiously because of the small sample size of palliative care professionals. However, it does provide suggestive evidence that communication techniques such as those mentioned above could be learned using dramatic enactments such as the one described. This could be done perhaps at the same time, and also without increasing costs of standardized patients, by incorporating action methods into communication skills teachings using conventional role-play http://cdn.coverstand.com/32431/209843/6ca444a86cd3d8e2df84d4cfc4c8999d0a1a8cd6.1.pdf#

Contrasting patient, family, provider, and societal goals at the end of life complicate decision making and induce variability of care after trauma

JOURNAL OF TRAUMA & ACUTE CARE SURGERY, 2014;77(2):262-267. Practitioner comfort and motivation to influence EoL [end-of-life care] decision making varies with experience level. ADs [advance directives] are not uniformly perceived to be helpful... To improve EoL quality, these factors need to be considered. Of [survey] respondents, 65.8% rely on family to make EoL decisions most or all of the time, while 80.7% feel family members are rarely or only sometimes in appropriate emotional states to make such choices. A significant number of practitioners felt comfortable making decisions without family input at all, more so with experienced practitioners as compared with those in practice for less than 15 years. Of the practitioners [who responded], 59.6% rely on ADs most or all of the time, only 61.1% agree or strongly agree that ADs are useful, and only 56.3% feel families follow their loved one's ADs most or all of the time. A patient's family support or ability to pay for aftercare was rarely or never considered important by 80.1% of the practitioners, despite 85.1% reporting that quality of life post-illness/injury was important most or all of the time. http://www.ncbi.nlm.nih.gov/pubmed/25058252

Of related interest:

- BMC HEALTH SERVICES RESEARCH | Online 31 July 2014 'The indispensable intermediaries: A qualitative study of informal caregivers' struggle to achieve influence at and after hospital discharge.' The care recipients' extensive frailty and increasing dependence on their families coupled with the complexity of health care services contribute to the perception of the informal caregivers' indispensable role as intermediaries. These findings accentuate the need to further discuss how frail older individuals and their informal caregivers can be supported and enabled to participate in decision-making regarding care arrangements that meet the care recipient's needs. http://www.biomedcentral.com/content/pdf/1472-6963-14-331.pdf
- COMMUNICATION MONOGRAPHS, 2014;81(3):261-284. 'Enacted goal attention in family conversations about end-of-life health decisions.' Most extant research on end-of-life communication in families has been based on the assumption that more communication is better communication. The authors used a multiple goals theoretical perspective to demonstrate that the quality of communication about end-of-life decisions matters. Using multilevel linear modeling, they found that outside ratings of a person's communication quality (i.e., attention to task, identity, and relational goals) as well as outside ratings of the partner's communication quality were positively associated with the person's reported conversational satisfaction and hopefulness and negatively associated with the person's hurt feelings and relational distancing. http://nca.tandfonline.com/doi/full/10.1080/03637751.2014.925568#.U9j9mONdX8I

How should a catholic hospice respond to patients who choose to voluntarily stop eating and drinking in order to hasten death?

THE LINACRE QUARTERLY | Online – 29 July 2014 –The practice of voluntarily stopping eating and drinking (VSED) in order to hasten death poses a unique problem for the Catholic hospice. Hospice staff may be confronted with patients already on their service who decide to pursue this option for ending their lives. Patients not on hospice service who are contemplating VSED are often advised to contact hospice for symptom palliation associated with the process of VSED. Intentionally hastening death not only violates the sanctity of human life and the Ethical & Religious Directives the Catholic hospice is bound to uphold, but it also runs counter to the general philosophy that hospice neither hastens nor postpones death. At the same time, hospice programs have a strong philosophy of non-abandonment of patients. This article analyzes the ethical issues from the perspective of the Catholic tradition and suggests strategies for the Catholic hospice to respond... http://www.maneyonline.com/doi/abs/10.1179/2050854914Y.00000000025

Noted in Media Watch, 14 April 2014, #353 (p.10):

■ JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2014;16(3):126-131. 'Hospice care for patients who choose to hasten death by voluntarily stopping eating and drinking.' Some hospice and palliative care organizations are considering the merits of creating policies to guide clinicians' responses to patient requests for information and support for a voluntarily stopping eating and drinking related hastened death. How clinicians understand the meaning of [such] requests ... and the legality and morality of the option will determine their responses. http://journals.lww.com/jhpn/Abstract/2014/05000/Hospice_Care_for_Patients_Who_Choose_to_Hasten.3.aspx

From the archives:

■ PALLIATIVE MEDICINE, 2006;20(7):703-710. 'Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals.' It is not uncommon for patients with advanced incurable disease to express a desire to hasten their death. Health professionals often have difficulty responding to such statements, and find it challenging to ascertain why these statements are made. Health professionals may struggle to determine whether a "desire to die" statement (DTDS) is about a request for hastened death, a sign of psychosocial distress, or merely a passing comment that is not intended to be heard literally as a death wish. Given the lack of guidelines to assist health professionals with this issue, the authors prepared multidisciplinary recommendations for responding to a DTDS, underpinned by key principles of therapeutic communication and a systematic review of empirical literature. [Noted in Media Watch, 17 March 2014, #349 (p.16, under 'Worth Repeating.')] http://pmj.sagepub.com/content/20/7/703.abstract

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.

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

Society of Critical Care Medicine and World Federation of Pediatric Intensive & Critical Care Societies

Integrating palliative care into the Pediatric ICU: A report from the improving palliative care in the ICU Advisory Board

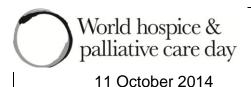
PEDIATRIC CRITICAL CARE MEDICINE | Online – 30 July 2014 – This review highlights benefits that patients, families and clinicians can expect to realize when palliative care [PC] is intentionally incorporated into the PICU. [PC] should begin at the time of a potentially life-limiting diagnosis and continue throughout the disease trajectory, regardless of the expected outcome. Although the PICU is often used for short term postoperative stabilization, PICU clinicians also care for many chronically ill children with complex underlying conditions and others receiving intensive care for prolonged periods. Integrating PC delivery into the PICU is rapidly becoming the standard for high quality care of critically ill children. Interdisciplinary ICU staff can take advantage of the growing resources for continuing education in pediatric PC principles and interventions. http://journals.lww.com/pccmjournal/Abstract/publishahead/Integrating Palliative Care Into the PICU A.99050.aspx

Of related interest:

- AAP (AMERICAN ACADEMY OF PEDIATRICS) NEWS, 2014;35(8):12. 'Continued growth [in the U.S.] anticipated for pediatric palliative care specialty.' The specialty of pediatric palliative care (PPC) is in the process of maturing. In 2000, the Academy published its first statement on 'Palliative Care for Children,' outlining a vision for what PPC should become. A recent national survey showed how the field has evolved over the past 12 years throughout the U.S. http://aapnews.aappublications.org/content/35/8/12.2.extract#
 - 'Palliative care for children,' Pediatrics, 2000;106(2):351-357. http://pediatrics.aappublications.org/content/106/2/351.full.pdf+html
 - 'Pediatric palliative care and hospice care commitments, guidelines and commitments,' Pediatrics, 2013;5(1):966-972. [Noted in Media Watch, 4 November 2013, #330 (p.13)] http://pediatrics.aappublications.org/content/132/5/966.full.pdf+html
- PEDIATRIC CLINICS OF NORTH AMERICA, 2014;61(4):719-733. 'Pediatric hospital care for children with life-threatening illness and the role of palliative care.' Under increasing pressure to contain costs, hospitals are challenged to provide high-quality care to an increasingly complex group of children with life-threatening illness (LTI) that often worsen over time. Pediatric palliative care is an essential component of optimal hospital care delivery for these children and their families. This article describes: 1) the current landscape of pediatric hospital care for children with LTI; 2) the connection between palliative care and hospital care for such children; and, 3) the relationship between health care reform and palliative care for children with LTI, http://www.pediatric.theclinics.com/article/S0031-3955(14)00071-6/abstract

N.B. This issue of *Pediatric Clinics of North America* includes several articles on pediatric palliative care. Journal contents page (scroll down to 'Pediatric Palliative Care'): http://www.pediatric.theclinics.com/current

N.B. Several recent articles on different aspects of pediatric palliative care are noted in Media Watch, 14 July 2014, #366 (pp.10-11).



Who Cares? We Do!

Home page: http://www.worldday.org/ Materials: http://www.worldday.org/materials/

A new paradigm is needed for medical education in the mid-twenty-first century and beyond: Are we ready?

RAMBAM MAIMONIDES MEDICAL JOURNAL, 2014;5(3):e0018. The twentieth century witnessed profound changes in medical education. All these changes, however, took place within the existing framework... The present paper suggests that we are approaching a singularity point, where we shall have to change the paradigm and be prepared for an entirely new genre of medical education. This is based upon analysis of existing and envisaged trends: first, in technology, such as availability of information and sophisticated simulations; second, in medical practice, such as far-reaching interventions in life and death that create an array of new moral dilemmas, as well as a change in patient mix in hospitals and a growing need of team work; third, in the societal attitude toward higher education. The structure of the future medical school is delineated in a rough sketch, and so are the roles of the future medical teacher. It is concluded that we are presently not prepared for the approaching changes, neither from practical nor from attitudinal points of view, and that it is now high time for both awareness of and preparation for these changes. http://www.rmmj.org.il/userimages/401/1/PublishFiles/406Article.pdf

Delivering bad news: An approach according to Jewish scriptures

RAMBAM MAIMONIDES MEDICAL JOURNAL, 2014;5(3):e0020. As the bearer of bad news, the physician is drawn into a human drama that contradicts *primum non nocere* [first, do no harm], one of the principal bioethic precepts that we learn as medical students. Delivering bad news often shocks the recipient(s), burdening the messenger with the difficult task to help them recover and cope with the emotional pain of a new and unwished-for reality. The authors present the elements: attention to the environment, the message format, the pace of the explanation, and the extent of details to be disclosed as principles with which to shape a methodology. http://www.rmmj.org.il/userimages/361/1/PublishFiles/391Article.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

CANADIAN MEDICAL ASSOCIATION (CMA) | Online – Accessed 30 July 2014 – End-of-life Care: A National Dialogue (Membership Consultation Report) A majority of the Association's members who participated ... favoured maintaining the current CMA policy opposing physician involvement in euthanasia and physician assisted dying. A significant minority felt this policy should at least be reviewed if not revised to support some form of physician-assisted dying... Others expressed the viewpoint it is premature to consider changing the law ... until a comprehensive and universal palliative care system is put in place. There was general acknowledgement Society would make the final decision concerning euthanasia and physician-assisted dying and that it was not the role of CMA or the medical profession to dictate what this should be. https://www.cma.ca/Assets/assets-library/document/en/advocacy/Englishreportfinal.pdf

Noted in Media Watch, 16 June 2014, #362 (p.1):

- THE GLOBE & MAIL | Online 10 June 2014 'Canada needs national palliative care plan, Canadian Medical Association urges.' The CMA is calling for the creation of a national palliative care strategy to ensure people across the country have access to a high-quality, dignified end-of-life experience. The Association is warning that strong safeguards must be put in place if physician-assisted dying is legalized in Canada. The association made the call in a new national end-of-life report created after speaking to Canadians across the country about their opinions on such highly charged as physician-assisted dying and palliative care.¹ http://www.theqlobeandmail.com/life/health-and-fitness/health/canadaneeds-national-palliative-care-plan-cma-urges/article19088848/
 - 'End-of-life care: A national dialogue,' CMA, based on town-hall meetings held across Canada in conjunction with Maclean's magazine, June 2014. http://www.cma.ca/multimedia/CMA/Content Images/CMAAdvocacy/EOL townhall_report_FINAL.pdf

■ THE PHARMACEUTICAL JOURNAL (U.K.) | Online – 26 July 2014 – 'Assistance to die.' How comfortable would you be to dispense a lethal dose for the purpose of ending the life of a dying patient? That is a dilemma pharmacists in the U.K. will need to consider if the assisted dying bill [i.e., the private member's bill introduced by Lord Falconer] is passed by parliament. http://www.pharmaceutical-journal.com/opinion/editorial/assistance-to-die/20065920.article

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2014/5/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 | Central Regional Hospice Palliative Care Program: http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1

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

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://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.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://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

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