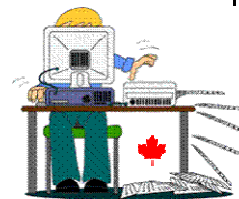


Media Watch...

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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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

Compiled & Annotated by Barry R. Ashpole

Responding to illness: Scroll down to [International](#) and 'Mind your language: "Battling" cancer metaphors can make terminally ill patients worse' (p.8), in the U.K. newspaper, *The Independent*.

Canada

End-of-life patients aren't being heard

THE GLOBE & MAIL | Online – 6 November 2014 – A gap between doctors' goals and patients' wishes may mean seriously ill patients are receiving aggressive forms of treatment that they don't actually want at the end of their lives, according to a new study. The study ... surveyed 233 older patients who were at risk of dying within the next six months, and 205 family members. These patients were from nine acute-care hospitals – not palliative-care facilities – in British Columbia, Alberta, Ontario and Quebec. It found patients' preferences for life-sustaining treatment and the orders that hospital teams gave about their resuscitation status were in agreement in only 30% of cases. In some instances, even though patients told researchers they did not want to be kept alive by artificial means, the orders written on their charts called for aggressive treatments, including cardiopulmonary resuscitation at all costs. In others, patients wanted health-care providers to switch to focusing on their comfort if they showed no signs of improvement, yet the prescribed orders were to provide full medical care. At

issue is the researchers' finding that health-care providers seldom talk to patients about their care as patients face the end of their lives. While patients said the most important issues were preferences for care, prognosis, the values that influence their decision-making, and fears or concerns, researchers found health-care providers infrequently discussed these issues with their patients. <http://www.theglobeandmail.com/life/end-of-life-patients-arent-being-heard/article21479080/>

Specialist Publications

'Withholding and withdrawing treatment in Canada: Implications of the Supreme Court of Canada's decision in the Rasouli case,' (p.11), in *Canadian Medical Association Journal*.

'Non-beneficial treatment [in] Canada: Definitions, causes, and potential solutions from the perspective of healthcare practitioners,' (p.14), in *Critical Medicine Medicine*.

Cont.

1. 'What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families,' *Canadian Medical Association Journal*, 3 November 2014. <http://www.cmaj.ca/site/press/cmaj140673.pdf>

Noted in Media Watch, 22 July 2013, #315 (p.2):

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 15 July 2013 – '**Just ask: Discussing goals of care with patients in hospital with serious illness.**' Engagement in regular audits of end-of-life communication and decision-making may help drive local quality improvement in the hospital setting. The authors suggest that parallel efforts be made about the limitations of life-sustaining technologies and the importance of advance care planning. <http://www.cmaj.ca/content/early/2013/07/15/cmaj.121274>

Government health care spending and how much seniors account for

THE GLOBE & MAIL | Online – 30 October 2014 – So far, the aging of Canada's population has been gradual, allowing the health-care system time to adjust. The Canadian Institute for Health Information report found that the aging of the population is only a modest cost driver, expected to be responsible for 0.9% of the health-care spending increase this year.¹ The proportion of health-care spending dedicated to seniors actually held nearly steady at around 45% between 2002 and 2012, even as the percentage of seniors in the population grew from 12.5% to 14.9%. The aging effect could become more pronounced, however, in 10 or 15 years, when baby boomers enter their mid-to-late 70s – the age at which an individual's cost to the system begins to rise dramatically. <http://www.theglobeandmail.com/life/health-and-fitness/health/government-health-care-spending-and-how-much-seniors-account-for/article21395533/>

Extract from the Canadian Institute for Health Information report

A few examples of the continuing trans-formation of the Canadian health care system include the introduction of interprofessional collaboration to provide team-based care, expansion in the scope of practice of some non-physician providers, increased focus on patient-centred care, emphasis on integration and continuity of care shifting to ambulatory and home care...

N.B. There is no mention in the Institute's report of end-of-life care, i.e., hospice or palliative care.

1. 'National Health Expenditure Trends, 1975 to 2014,' Canadian Institute for Health Information, October 2014. http://www.cihi.ca/web/resource/en/nhex_2014_report_en.pdf

Representative sample of articles on health care spending in Canada in the context of an ageing population noted in past issues of Media Watch:

- *HEALTHCARE POLICY*, 2011;7(1):68-79. '**Population aging and the determinants of healthcare expenditures: The case of hospital, medical and pharmaceutical care in British Columbia, 1996 to 2006.**' Population aging has exerted, and will continue to exert, only modest pressures on medical, hospital and pharmaceutical costs in Canada. [Noted in Media Watch, 5 September 2011, #217 (p.1)] <http://www.longwoods.com/content/22525>
- *HEALTHCARE PAPERS*, 2011;11(1):8-18. '**An evidence-based policy prescription for an aging population.**' The authors note that aging *per se* will only have a modest impact on future healthcare costs and that other factors, such as increased medical interventions, changes in technology, and increases in overall service use, will be the main cost drivers. [Noted in Media Watch, 9 May 2011, #200 (p.1)] <http://www.longwoods.com/content/22246>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 6 November 2014 – '**The story behind the Canadian Medical Association's overwhelming change on assisted death.**' With Quebec set to implement its comprehensive medical aid in dying law, the Supreme Court of Canada expected to hand down a ruling on assisted suicide, and opinion polls registering overwhelming support for legalizing the right to die, the Canadian Medical Association [CMA] ... is adjusting to the new reality. In August, the membership of the CMA voted 91% in favour of allowing doctors to follow their conscience if PAD is legalized. Then, in October, the CMA told the Supreme Court it was changing its long-standing policy that "Canadian physicians should not participate in euthanasia or assisted suicide." <http://www.theglobeandmail.com/life/health-and-fitness/health/the-story-behind-the-cmas-sweeping-change-on-assisted-death/article21479744/>

[U.S.A.](#)

Right to try laws

For the dying, state laws offer hope that critics call hollow

ARIZONA | *Modern Health Care* – 5 November 2014 – Amid a tidal wave of Republican election wins, supporters of so-called right-to-try laws claimed victory as Arizona overwhelmingly approved a measure that will allow dying patients to get drugs and medical devices not yet approved by the Food & Drug Administration. Arizona became the fifth state in the country to approve a right-to-try law, and the first to pass it by voter referendum. Lawmakers in Colorado, Louisiana, Missouri and Michigan have all passed similar laws by overwhelming majorities over the past several months, and the state Legislature in Nevada is expected to consider a bill next year. <http://www.modernhealthcare.com/article/20141105/NEWS/311059922/for-the-dying-state-laws-offer-hope-that-critics-call-hollow>

[Specialist Publications](#)

'Trends in the use of volunteers in U.S. hospices: 2000 to 2010' (p.10), in *American Journal of Hospice & Palliative Medicine*.

'Cost savings and enhanced hospice enrollment with a home-based palliative care program implemented as a hospice-private payer partnership,' (p.13), in *Journal of Palliative Medicine*.

'Advanced illness care: Issues and options [in the U.S.]' (p.15), in *Public Policy Aging Report*.

Caregiver medical leave from work not guaranteed, often unpaid

REUTERS HEALTH | Online – 5 November 2014 – The U.S. is the only developed country without paid sick leave policies for all workers and their families, which increases burdens on the millions balancing work with caregiving for an older family member, according to a new review.¹ Mei-Lan Chen of the School of Nursing at the University of North Carolina, Greensboro, reviewed the Family & Medical Leave Act, enacted in 1993, including how it works in practice and the types of employees it leaves behind. There were some 67 million unpaid caregivers in the U.S., and two thirds of adults with disabilities got all their care and assistance from family members. In just 15 years, she notes, older Americans will make up 20% of the population, with one in 13 over age 85. "Clearly, we should seriously consider what price we will need to pay for an aging society if we decide not to enact paid sick and family leave laws," Chen writes. <http://uk.reuters.com/article/2014/11/05/us-health-caregivers-family-leave-idUKKBN0IP2YR20141105>

Cont.

1. 'The growing costs and burden of family caregiving of older adults: A review of paid sick leave and family leave policies,' *The Gerontologist*, 21 October 2014. Policy recommendations including the exemplar of the San Francisco Paid Sick Leave Ordinance, and suggestions for more comprehensive policies are proposed for federal, state, and/or city legislation. <http://gerontologist.oxfordjournals.org/content/early/2014/10/20/geront.gnu093.short?rss=1>

Noted in Media Watch, 3 November 2014, #382 (p.14):

- *MEDICAL XPRESS* | Online – 27 October 2014 – **'Cost of informal caregiving for U.S. elderly is \$522 billion annually, study finds.'** The price tag for informal caregiving of elderly people by friends and relatives in the U.S. comes to \$522 billion a year, according to a new study. <http://medicalxpress.com/news/2014-10-caregiving-elderly-billion-annually.html>

Home health, hospice RNs needed as population ages

TEXAS | *The Houston Chronicle* – 5 November 2014 – The U.S. Department of Health [& Human Services] projects that 800,000 health care providers and 1 million new nurses will be needed to fill vacancies left by retirees by 2020... This report further points out the number of people working as personal care aides (non-RNs) alone already has grown from 534,000 to 985,000 between 2002 and 2012 – an increase of 118%. By 2022, this explosion of available jobs is expected to grow by an additional 50%, adding 581,000 more personal care positions ... to the U.S. health care sector. Whether working with a patient in a private residence, in a skilled nursing or hospice setting, RNs not only increase quality of daily living and management of chronic condition but provide peace of mind to family/caregivers. <http://www.chron.com/jobs/article/Home-health-hospice-RNs-needed-as-population-ages-5872755.php>

Noted in Media Watch, 29 September 2014, #377 (p.2):

- MICHIGAN | *Grand Rapids Business Journal* – 26 September 2014 – **'Training in hospice and palliative care a "huge need."** There has already been a tremendous amount of attention given to the looming doctor and nursing shortage, and hospice and palliative care are already behind when it comes to the number of caregivers in the profession. That is, in part, because hospice and palliative care are relatively new fields. <http://www.grbj.com/articles/80666-training-in-hospice-and-palliative-care-a-huge-need>

New hospital job: Patient satisfaction officer

THE WASHINGTON POST | Online – 3 November 2014 – Two years ago, Inova Health System [Falls Church, Virginia] recruited a top executive who was not a physician, had never worked in hospital administration, and barely knew the difference between Medicare and Medicaid. What Paul Westbrook specialized in was customer service. His background is in the hotel business – Marriott and the Ritz-Carlton, to be precise. He is one of dozens of hospital executives around the country with a new charge. Called chief patient experience officers, their focus is on the service side of hospital care: improving communication with patients and making sure staff are attentive to their needs, whether that's more face time with nurses or quieter hallways so they can sleep. It's a dimension of hospital care that has long been neglected, patient advocates say, and it was put high on hospitals' agendas only when Medicare started tracking patient satisfaction... http://www.washingtonpost.com/national/health-science/new-hospital-job-patient-satisfaction-officer/2014/11/03/ed244104-5301-11e4-892e-602188e70e9c_story.html

Noted in Media Watch, 27 October 2014, #381 (p.3):

- NORTH CAROLINA | *The Charlotte Observer* – 20 October 2014 – **'Patient experience officers aim to improve communication.'** As chief patient experience officer for Carolinas HealthCare System, Connie Bonebrake [a social worker by training] is working to improve physician-patient communication. http://www.charlotteobserver.com/2014/10/18/5250844/patient-experience-officers-aim.html#.VET19SLF_YQ

International

Premature babies: Resuscitation guidelines are under review

AUSTRALIA & NEW ZEALAND | *The Sydney Morning Herald* (Australia) – 9 November 2014 – The Australian & New Zealand Neonatal Network is planning to depart from conventional wisdom by taking into account the myriad factors that predict mortality and morbidity, rather than rely on gestational age alone. It will be similar to the risk matrix used in the U.S., which takes into account weight, gender, multiple birth status, and whether the mother has taken antenatal corticosteroids. The Australian version would use local data and also consider whether the baby was to be born in a hospital with an intensive care unit. It will be a useful tool to predict mortality and help counsel parents through what may be the most difficult decision of their lives. But there will still be a "zone of parental discretion" based on the percentage that it produces. And it will not replace the internal risk matrix that the parents of these borderline babies must apply to their own circumstances. For end-of-life care, the cost of keeping somebody alive must be pressed against the sum total of their experiences, the people that they love, their imprint on the world, to reach an impossible estimation on the value of their life. With premature babies this process is performed in reverse. <http://www.smh.com.au/national/health/premature-babies-resuscitation-guidelines-are-under-review-20141106-11hf47.html>

Doctor condemns "torture" caused by Taiwan's end of life policies

TAIWAN | *Focus Taiwan* – 7 November 2014 – Taipei Doctor Chen Hsiu-tan of National Yang-ming University Hospital said after a legislative hearing ... that Taiwan needs to take stock of the pain its end of life policies are inflicting on the living and those being kept artificially alive. Patients should have the right to choose to leave the world in dignity instead of having to accept futile medical treatment, said Chen, a long-time hospice care advocate, after reporting on hospice care at a legislative hearing. Citing a survey, Chen said that one-third of terminally ill patients in Taiwan were "tortured" by such futile treatment as resuscitation, respirators, kidney dialysis and extra-corporeal membrane oxygenation before their last breath, causing pain to the living as well as the dead. <http://focustaiwan.tw/news/asoc/201411070028.aspx>

Noted in Media Watch, 8 July 2013, #313 (p.5):

- TAIWAN | *The Taipei Times* – 8 July 2013 – **'Government looks into "futile care."** With a rapidly aging population and a cash-strapped National Health Insurance system, the government is paying more attention to the issue of "futile medical care," treatment applied only to prolong life without a foreseeable cure or positive outcome, and the prospect of hospice care. <http://www.taipetimes.com/News/taiwan/archives/2013/07/08/2003566617>



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>

End-of-life care in England

Health Committee announce inquiry into end of life care

U.K. (England) | Health [Parliamentary Select] Committee – 5 November 2014 – In June 2014 the Department of Health announced a new approach for those caring for dying people in England during the last days of their life.¹ The approach focuses on achieving five Priorities of Care that should be applied whenever and wherever someone is dying, whether in hospital, a hospice, their own home... The Health Committee has decided to take a broader look at the issue of palliative and end-of-life care. The committee will examine the way that health and social care services, and the voluntary and community sector, support people who are likely to die within 12 months, what opportunities exist for better integration and for improving care quality, and the experience of those caring for people at the end of life. It will review the definitions of, and distinctions

between, "palliative" and "end-of-life" care to examine how to provide more effective targeting of resources and management of interventions necessary to bring about service change. The inquiry will examine palliative and end of life care for adults, including the frail elderly, and children and young people. <http://www.parliament.uk/business/committees/committees-a-z/commons-select/health-committee/news/end-of-life-inquiry-launch/>

Specialist Publications

'Two decades of British newspaper coverage regarding do-not-attempt-cardiopulmonary resuscitation decisions: Lessons for clinicians' (p.15), in *Resuscitation*.

1. '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>

Of related interest:

- U.K. (England, Northern Ireland, Scotland & Wales) | *The Daily Telegraph* – 3 November 2014 – **'Nurses "do not have time to care properly for the dying."** Nine in ten nurses feel unable to care for dying patients properly and fulfil their last wishes, according to a new poll. The Royal College of Nursing said many staff were "profoundly troubled" by an inability to give good end-of-life care, because they had too little time, and in some cases, lacked training. The College survey, which had more than 7,000 responses, found that 59% [of respondents] found that the wishes of patients could not be fulfilled during their last six months. Almost half of nurses said they did not always get the chance to speak to patients about how they would like to be cared for in their final days. Almost 70% of respondents said they had seen cases where a person was taken to hospital against their wishes because the resources to care for them at home were not in place. <http://www.telegraph.co.uk/health/healthnews/11203802/Nurses-do-not-have-time-to-care-properly-for-the-dying.html>
- U.K. | *Public Finance* – 3 November 2014 – **'No living wage for homecare workers?'** Many homecare workers are not going to benefit from today's rise in the Living Wage – indeed they are lucky to get the National Minimum Wage. Councils must do more to ensure homecare workers are properly remunerated. With a 20 pence an hour increase in the Living Wage to £7.85 just announced, it's time to spare a thought for an important group of workers who will be lucky to see the National Minimum Wage of £6.50 pence an hour in their pay packets this week. <http://opinion.publicfinance.co.uk/2014/11/no-living-wage-for-homecare-workers/>

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.

End-of-life care in Australia

Palliative care offered in mother tongue

AUSTRALIA (Victoria) | *The Northern Weekly* (Keilor Park) – 4 November 2014 – A palliative care program for Arabic-speaking patients was launched ... [by] ... the Victorian Arabic Social Services [VASS]... Health Minister David Davis announced a new, culturally-sensitive palliative care community education initiative,¹ which will share \$34.4 million committed to strengthening services for the terminally ill. VASS staff and volunteers took part in training sessions to become accredited bilingual educators, who can now teach the Arabic-speaking elderly about what palliative care options are available to them. <http://www.northernweekly.com.au/story/1813765/broadmeadows-palliative-care-offered-in-mother-tongue/>

1. Initiatives by the Culturally Responsive Palliative Care Project, jointly led by Palliative Care Victoria and the Ethnic Communities Council of Victoria, target culturally and linguistically diverse communities, for example, Arabic, Chinese, Croatian, Greek Macedonian, Italian, Maltese, Polish, Turkish and Vietnamese.

End-of-life care in the Czech Republic

Most people would rather die at home than in hospital, according to a poll

CZECH REPUBLIC | Czech News Agency – 3 November 2014 – The Regional Development Ministry has approved the standards for the new qualification of guides to the dying, in reaction to the fact that many people wish to die at home... According to the latest STEM/MARK poll, almost nobody wants to die in hospital. The poll also showed that 55% start thinking about the end of life only after they get seriously ill, 61% never discuss their dying with anybody, and only 36% are willing to talk with their family about their idea of the circumstances and treatment related to the period preceding their own death... <http://praguepost.com/czech-news/42426-ministry-to-offer-certificate-for-guide-to-the-dying>

End-of-life care in Ireland

New report highlights deficiencies in palliative care needs of people with advancing neurological disease

IRELAND | Irish Hospice Association – 3 November 2014 – Currently there are 700,000 people in the country living with a neurological condition and many of those with progressive neurological conditions will need access to palliative care. However, a new [*sic*] report ... has identified deficiencies in the current level of service available.¹ The report is calling for protocols and pathways to be developed, and increased resourcing and training opportunities for neurology and specialist palliative care services to support people with advancing neurological disease. There is a need for earlier referral of patients to palliative care services and advises that a multi-disciplinary care approach is needed

for those suffering from neurological conditions. <http://hospicefoundation.ie/new-report-highlights-deficiencies-in-palliative-care-needs-of-people-with-advancing-neurological-disease/>

Specialist Publications

'The need for palliative care in Ireland: A population-based estimate of palliative care using routine mortality data, inclusive of non-malignant conditions' (p.13), in *Journal of Pain & Symptom Management*.

1. 'The Palliative Care Needs of People with Advancing Neurological Disease in Ireland,' A report prepared for the Neurological Alliance of Ireland and the Irish Hospice Foundation, June 2014. <http://hospicefoundation.ie/wp-content/uploads/2014/11/NAI-IHF-report1.pdf>

Cont.

Representative sample of articles on end-of-life care for people living with a neurological condition noted in past issues of Media Watch:

- *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. [Noted in Media Watch, 9 June 2014, #361 (p.15)] <http://www.medscape.com/viewarticle/826100>
- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(2):57. '**Reflections on neurological palliative care.**' Neurological palliative care has led the authors to consider new aspects of care, new interventions, different symptoms and challenging issues, setting an example for how palliative care services should deal with non-cancer diagnoses. [Noted in Media Watch, 17 March 2014, #349 (p.10)]

N.B. Access to this article requires a subscription.
<http://www.haywardpublishing.co.uk/ejpc.aspx>
- *NEUROLOGY*, 2014;82(7):640-642. '**Emerging subspecialties in neurology: Palliative care.**' Individuals with conditions including stroke, multiple sclerosis, Parkinson disease, muscular dystrophies, amyotrophic lateral sclerosis, and nervous system malignancies share a host of physical, emotional, and existential symptoms difficult to treat. [Noted in Media Watch, 24 February 2014, #346 (p.13)] <http://www.neurology.org/content/82/7/640.extract>

Knesset committee passes bill allowing parents of seriously ill children 90 days off work per year

ISRAEL | *The Jerusalem Post* – 3 November 2014 – The Labor, Welfare & Health Committee unanimously passed the first reading of a bill ... that would enable parents of sick children requiring constant treatments to take up to 90 days off work per year. The bill ... aims to expand on the current law allowing parents of children with terminal illnesses time off of work. The proposed bill would enable parents with children receiving dialysis or regular treatments for severe illnesses to bank their vacation and sick days and take up to 90 days off of work. <http://www.jpost.com/Israel-News/Health/Knesset-committee-passes-bill-allowing-parents-of-seriously-ill-children-90-days-off-work-per-year-380660>

Mind your language: "Battling" cancer metaphors can make terminally ill patients worse

U.K. | *The Independent* – 3 November 2014 – Media portrayals of cancer as a "battle to be fought" are leading to feelings of failure and guilt among terminally ill patients, experts in language and end-of-life care have said. Obituaries should not refer to people "losing their battle against cancer" and doctors should also avoid "imposing" the term on patients who may end up feeling personally responsible if their condition deteriorates, they said. Interviews and analysis of blog posts by patients, carers and health professionals led researchers at the University of Lancaster to conclude that war metaphors were unhelpful for many patients. While talking about "fighting" cancer could be useful for some, it should be for the patient themselves to introduce the metaphor, said Elena Semino, professor of linguistics and verbal art at Lancaster. Her study, which was carried out alongside palliative care specialists, analysed 1.5m words of discussion, representing the views of around 200 people closely involved with cancer care. Professor Semino, who carried out the study at Lancaster's Economic & Social Research Council Centre for Corpus Approaches to Social Science, is now working with the National Health Service to produce a "metaphor manual." <http://www.independent.co.uk/life-style/health-and-families/health-news/mind-your-language-battling-cancer-metaphors-can-make-terminally-ill-patients-worse-9836322.html>

Cont.

Noted in Media Watch, 28 April 2014, #355 (p.2):

- U.S. | *The New York Times* – 22 April 2014 – **'Fighting words are rarer among British doctors.'** We talked recently about the bellicose expressions often used in discussing the end of life¹ – the well-intended encouragement to "keep fighting," to declare someone a "fighter," to never "give up." And then ... to describe him or her as having "lost the battle" with a disease. That post led me to researchers at Lancaster University in England, who have been analyzing the actual language patients, caregivers and health care professionals use to describe responses to disease.² http://newoldage.blogs.nytimes.com/2014/04/22/fighting-words-are-rare-among-british-doctors/?_php=true&_type=blogs&ref=health&r=0
 1. *THE NEW YORK TIMES* | Online – 11 April 2014 – **'Wounded by the language of war.'** When did the language we use to talk about death start to resemble a Pentagon briefing, full of military references and combat analogies? [Noted in Media Watch, 21 April 2014, #354 (p.5)] <http://newoldage.blogs.nytimes.com/2014/04/11/wounded-by-the-language-of-war/?ref=health>
 2. Metaphor in End-of-Life Care Project, Lancaster University: <http://ucrel.lancs.ac.uk/melc/>

End-of-life care in Wales

Private palliative and social care providers face scrutiny

U.K. (Wales) | BBC News (Cardiff) – 2 November 2014 – People receiving privately-arranged social services and palliative care services in Wales will be able to file complaints under new rights. Previously, the Public Services Ombudsman for Wales has only had powers to investigate such services provided by a council or local health board. But changes to the law made by the Welsh government mean private providers can now be scrutinised as well. About 75% of the 32,000 people who die in Wales annually have palliative care. A survey published on Tuesday showed families and patients rated palliative care services 9.56 out of 10.¹ <http://www.bbc.com/news/uk-wales-29849847>

1. 'Together for Health End-of-Life Care Delivery Plan: Annual Report 2014,' Health in Wales, Welsh Government, November 2014. [Noted in Media Watch, 3 November 2014, #382 (p.8)] <http://wales.gov.uk/docs/dhss/publications/141024reporten.pdf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Daily Telegraph* – 7 November 2014 – **'Assisted dying: Judges could decide whether terminally ill should be allowed to die.'** Leading opponents of euthanasia have signalled that they could accept a system of assisted dying in which judges rather than doctors take the final decision. Lord Carlile QC and Baroness Butler-Sloss, former head of the High Court Family Division – both vocal critics of the former Lord Chancellor, Lord Falconer's Assisted Dying Bill – called for judicial safeguards to prevent vulnerable people being pressurised to end their life. The shift came as the House of Lords unanimously backed key amendments giving a High Court judge a role in any future system of assisted suicide in the U.K., during detailed scrutiny of Lord Falconer's proposals. <http://www.telegraph.co.uk/news/uknews/assisted-dying/11216541/Assisted-dying-judges-could-decide-whether-terminally-ill-should-be-allowed-to-die.html>

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[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>

Of related interest:

- U.K. | BBC News – 6 November 2014 – **'Amendments slow bill's progress.'** Is the Assisted Dying Bill about to be smothered under a cascade of amendments? Last week, when there were 40 amendments down on his bill to allow terminally-ill people to end their own lives, the former Lord Chancellor, Lord Falconer, told me he wasn't shouting "Filibuster!" He might be now. The latest list of amendments runs to 175 – and he may even need a couple of days to get the bill through committee stage. <http://www.bbc.com/news/uk-politics-29941585>
- U.K. | Press Association – 5 November 2014 – **'Poll reveals right-to-die concerns.'** The public backs the principle of state-assisted suicide for the terminally ill but has serious concerns that in practice the system would be open to abuse, put undue pressure on the elderly to end their lives, and be extended to other groups such as the disabled, a poll found.¹ <https://uk.news.yahoo.com/poll-reveals-die-concerns-000204328.html#OUvctd7>
 1. 'Health & Assisted Dying Poll,' ComRes, November 2014. http://www.comres.co.uk/polls/Not_Dead_Yet_CNK_Poll_November_2014.pdf
- INDIA | *The Times of India* – 5 November 2014 – **'One in 5 suicides in India is due to chronic illness.'** Shame and pain caused by an ailment was the reason for one in every five suicides in India last year. The number of people with cancer committing suicide has seen a significant jump, with Kerala taking the lead with 155 such cases. Dr. C S Mani of Cancer Research & Relief Trust said patients who come to him feel "setbacks" at multiple levels: during diagnosis, when they have a relapse and when they are recommended palliative care. "There comes a point when there is no cure as chemotherapy and medication have proved ineffective. <http://timesofindia.indiatimes.com/india/One-in-5-suicides-in-India-is-due-to-chronic-illness/articleshow/45041564.cms>
- ITALY | *The Local* (Stockholm, Sweden) – 4 November 2014 – **'460 Italians sought 'right to die' in 2013.'** Some 460 Italians, who were either terminally sick or suffering from debilitating illnesses, tried to end their lives at "right to die" clinics in Switzerland last year. Despite a growing number of Italians seeking assisted suicide ... only fifty have succeeded in ending their lives in Switzerland over the last three years, while 27 are on the waiting list. <http://www.thelocal.it/20141104/hundreds-of-italians-sought-right-to-die-in-2013>

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

Trends in the use of volunteers in U.S. hospices: 2000 to 2010

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 3 November 2014 – Using a longitudinal sample of freestanding Medicare-certified hospices in the 50 U.S. states and the District of Columbia, this study sought to explore the factors associated with volunteer demand and describe how volunteer use has changed from 2000 to 2010. A temporal decline in the extent of use of volunteers in freestanding hospices was observed... Findings indicated both organizational and environmental factors influence the use of volunteers... Given the importance of volunteers, both in the preservation of hospices' philanthropic traditions and in reducing health care expenditure at the end of life, research is needed to further evaluate factors associated with this decline. Emphasis should be placed on improving the retention of the existing hospice volunteer workforce. <http://ajh.sagepub.com/content/early/2014/10/31/1049909114557351.abstract>

Representative sample of articles on hospice volunteers noted in past issues of Media Watch:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 July 2012 – **'Holding on to what you have got: Keeping hospice palliative care volunteers volunteering.'** The items that received the highest mean importance ratings [in this study] included enjoying the work they do, feeling adequately prepared/trained, and learning from their patients' experiences/listening to their patients' life stories. [Noted in Media Watch, 23 July 2012, #263 (p.6)] <http://ajh.sagepub.com/content/early/2012/07/16/1049909112453643.abstract>

Cont.

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 January 2012 – **'Should I stay or should I go: A study of hospice palliative care volunteer satisfaction and retention.'** Volunteers said that feeling appreciated by the patients/families they support gave them great satisfaction. [Noted in Media Watch, 16 January 2012, #236 (p.5)] <http://ajh.sagepub.com/content/early/2012/01/04/1049909111432622.abstract>

Socioeconomic factors associated with post-hospitalization hospice care settings: A 5-year perspective

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 3 November 2014 – Investigating whether socioeconomic characteristics determine if hospice is received at home or in a medical facility is important to examine, considering most patients prefer to die at home. The results [of this study] indicate increasingly patients are being discharged to home and overall socioeconomic characteristics appear to have less of an influence over where hospice is [received] ... <http://ajh.sagepub.com/content/early/2014/10/31/1049909114556877.abstract>

Factors affecting the successful implementation and sustainability of the Liverpool Care Pathway for dying patients: A realist evaluation

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 7 November 2014 – The Liverpool Care Pathway (LCP) for the dying patient was designed to improve end-of-life care in generalist healthcare settings. Controversy has led to its withdrawal in some jurisdictions. The main objective of this research was to identify the influences that facilitated or hindered successful LCP implementation. There is a need to appreciate the organisationally complex nature of intervening to improve end-of-life care. Successful implementation of evidence-based interventions for end-of-life care requires commitment to planning, training and ongoing review that takes account of different perspectives, institutional hierarchies and relationships, and the educational needs of professional disciplines. There is a need also to recognise that medical consultants require particular support in their role as gatekeepers and as a lead communication channel with patients and their relatives. <http://spcare.bmj.com/content/early/2014/11/07/bmjspcare-2014-000723.abstract>

Withholding and withdrawing treatment in Canada: Implications of the Supreme Court of Canada's decision in the Rasouli case

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 4 November 2014 – In Ontario, physicians must obtain consent to withdraw life support in cases like that of Hassan Rasouli, even where such treatment is thought to be non-beneficial. Consent may or may not be required to withdraw other treatment or to withhold treatment. If the decision is applied in other cases in Ontario, whether consent is required may be based on the need for immediate additional treatment, physical contact with the patient and anticipation of death shortly after a withdrawal of life-sustaining treatment. Considering the rationale of the Supreme Court's decision in the Rasouli case ... the authors argue that consent is not required to withhold non-beneficial cardiopulmonary resuscitation, but appropriate processes, including those related to communication, must be followed. <http://www.cmaj.ca/content/186/16/E622.extract>

Noted in Media Watch, 8 September 2014, #374 (p.8):

- *CANADIAN JOURNAL OF ANESTHESIA* | Online – Accessed 2 September 2014 – **'The future of decision-making in critical care after *Cuthbertson v. Rasouli*.'** The Supreme Court of Canada ruling on *Cuthbertson v. Rasouli* has implications for all acute healthcare providers. The authors' objective in writing this article is to clarify the implications of this ruling on the care of critically ill patients. <http://link.springer.com/article/10.1007/s12630-014-0215-9>

Palliative care and cystic fibrosis – the benefits of integrated working

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2014;21(6):277-281. Many challenges face those involved in the delivery of palliative care in non-cancer settings; these are particularly evident in the care of adults with cystic fibrosis (CF), exacerbated by a paucity of research in the methods of palliative care for this patient group. Palliative care and CF teams can work together to provide synergistic care and treatment for CF patients and their families, and when this is done well there are huge benefits for patients and families/carers, as well as for health care professionals. Palliative care involvement for CF patients, and indeed other patients whose disease progression is complex, may benefit from being viewed as a fluid interface rather than a finite transition from one team to another.

N.B. Access to this article requires a subscription. Journal contents page:

http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2014&Edition=519

Core competencies for palliative care social work in Europe: An European Association for Palliative Care White Paper – Part 1

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2014;21(6):300-305. This White Paper is the culmination of work undertaken ... to examine the diversity of roles, tasks and education of palliative care social workers in Europe. One of the stated objectives ... was to complete a consensus White paper before considering generalist and specialist social work education curricula. The authors propose a competence framework that is applicable to social workers in any role, but specifically delineates the advanced competencies appropriate to specialist work required in palliative and end-of-life care. This paper does not itemise the curricula required for social work training in palliative care; this will be addressed in a second phase of work.

N.B. Access to this article requires a subscription. Journal contents page:

http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2014&Edition=519

The lung cancer patient, the pneumologist and palliative care: A developing alliance

EUROPEAN RESPIRATORY JOURNAL | Online – 30 October 2014 – Considerable evidence is now available on the value of palliative care for lung cancer patients in all stages and at all times during the course of the disease. However, pneumologists and their institutions seem to be widely in arrears with the implementation of palliative care concepts and the development of integrated structures. This review focuses on the available evidence and experience of various frequently unmet needs of lung cancer patients, especially psychological, social, spiritual and cultural ones. This review draws pneumologists' attention to improving their skills in communication with the patients, their relatives and among themselves, and to establish team structures with more far-reaching competences and continuity than existing multilateral co-operations and conferences can provide. <http://erj.ersjournals.com/content/early/2014/10/30/09031936.00072514.abstract>

Noted in Media Watch, 27 May 2013, #307 (p.8):

- *THE LANCET RESPIRATORY MEDICINE* | Online – 17 May 2013 – '**Palliative care for lung disease: Start early, stay late.**' At the end of life when all reasonable curative interventions have failed, many patients with end-stage lung disease still die in pain after much suffering. [http://www.thelancet.com/journals/lanres/article/PIIS2213-2600\(13\)70083-3/fulltext#article_upsell](http://www.thelancet.com/journals/lanres/article/PIIS2213-2600(13)70083-3/fulltext#article_upsell)

Sedation at the end of life: A hospice's decision-making practices in the U.K.

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2014;20(10):474-481. This article details the evolution of sedation decision-making practices at a 14-bedded U.K. hospice over the course of 5 years... Key areas, such as documented consideration of hydration status and discussion with family members, have been improved following the implementation of a checklist of decision-making prompts, demonstrating how practice can be improved and sustained over time. <http://www.magonlinelibrary.com/doi/abs/10.12968/ijpn.2014.20.10.474>

When is it okay to cry? An end-of-life simulation experience

JOURNAL OF NURSING EDUCATION, 2014;53(11):659-662. This article details how a small college of nursing affiliated with a faith-based health care corporation integrated the education of end-of-life care into a mega code simulation. Students participated in a high-fidelity simulated mega code scenario in which the simulator died. Following de-briefing, student groups participated in an additional scenario in which faculty coached them through post-mortem care and interaction with a family member and a hospital chaplain. As a result of this multidimensional, inter-professional simulation, students developed heightened skill in applying basic life-saving measures, increased knowledge of and comfort with post-mortem care, and increased awareness of the emotions elicited by the experience. <http://europepmc.org/abstract/med/25350901>

The need for palliative care in Ireland: A population-based estimate of palliative care using routine mortality data, inclusive of non-malignant conditions

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 November 2014 – Over the history of palliative care provision in Ireland, services have predominantly provided care to those with cancer. Previous estimates of palliative care need focused primarily on specialist palliative care and included only a limited number of non-malignant diseases. During the period 2007-2011, there were 141,807 deaths. Eighty percent were from conditions recognized as having associated palliative care needs, with 41,253 (30%) deaths from cancer and 71,226 (50%) deaths from non-cancer conditions. The majority of deaths, 81% (91,914), were among those ≥ 65 years. There was a 13.9% (901) increase in deaths of those ≥ 85 years. Deaths from dementia increased by 51.3%, with an increase in deaths from neurodegenerative disease (42.8%) and cancer (9.5%). Future palliative care policy decisions in Ireland must consider the rapidly aging Irish population with the accompanying increase in deaths from cancer, dementia and neurodegenerative disease and associated palliative care need. New models of palliative care may be required to address this. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00548-X/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00548-X/abstract)

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

Cost savings and enhanced hospice enrollment with a home-based palliative care program implemented as a hospice-private payer partnership

JOURNAL OF PALLIATIVE MEDICINE | Online – 6 November 2014 – In the U.S., 5% of the population is responsible for nearly half of all health care expenditures, with a large concentration of spending driven by individuals with expensive chronic conditions in their last year of life. Outpatient palliative care under the Medicare Hospice Benefit excludes a large proportion of the chronically ill and there is widespread recognition that innovative strategies must be developed to meet the needs of the seriously ill while reducing costs. Cost savings were apparent [in this study] in the last three months of life – \$6,804 per member per month cost for palliative care participants versus \$10,712 for usual care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0184>

Medical futility and non-beneficial interventions

MAYO CLINIC PROCEEDINGS | Online – 28 October 2014 – Medical futility is a clinically relevant and controversial issue. In 2005, 87% of Canadian intensivists surveyed believed that they had provided futile medical interventions during the past year. A 2013 study of 5 academic intensive care units found that physicians considered nearly 20% of all interventions provided over a 3-month period to be futile. The duration of futile interventions ranged from 1 to 58 days, with an estimated cost of \$2.6 million during the 3-month study. More than half of the cases were considered futile because even with intervention the physician believed that the patient's goals were unreachable. [http://www.mayoclinicproceedings.org/article/S0025-6196\(14\)00793-9/abstract](http://www.mayoclinicproceedings.org/article/S0025-6196(14)00793-9/abstract)

Of related interest:

- *ANNALS OF THE NEW YORK ACADEMY OF SCIENCES* | Online – 28 October 2014 – **'Life, death, and the bridges in-between.'** When effective treatment options are exhausted, technological advances can be burdensome bridges to death. This paper briefly reviews the principles of management of life-threatening critical illness and the corresponding biological aspects of life, death, and organ donation, which are both informed and complicated by these technological and scientific achievements. <http://onlinelibrary.wiley.com/doi/10.1111/nyas.12564/full>
- *CRITICAL CARE MEDICINE* | Online - 5 November 2014 – **'Non-beneficial treatment [in] Canada: Definitions, causes, and potential solutions from the perspective of healthcare practitioners.'** Canadian nurses and physicians perceive current means of resolving non-beneficial treatment are inadequate, and we need to adopt new techniques of resolving non-beneficial treatment. Most promising strategies to reduce non-beneficial treatment are felt to be improved advance care planning and communication training for healthcare professionals. http://journals.lww.com/ccmjournal/Abstract/publishahead/Nonbeneficial_Treatment_Canada_Definitions..97412.aspx

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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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.

Advanced illness care: Issues and options [in the U.S.]

PUBLIC POLICY & AGING REPORT, 2014; 24(3):79-80. A number of developments addressing advanced illness have gained traction in recent years. These include the central place of person- and family-centered care, consensus on the need for improved care coordination, and the advent of the medical home and other Centers for Medicare & Medicaid-stimulated and funded delivery system demonstrations. The combined contributions of the Coalition to Transform Advanced Care, Bipartisan Congressional legislative initiatives, the Coalition to End Unwanted Medical Treatment, and additional initiatives ... provide clear evidence that policy makers and stakeholders are now actively engaged in a discussion of advanced illness care beyond the presumptiveness of "end-of-life care" and the ignorance associated with "death panel" allegations. "Advanced illness" is defined as the period of illness when functioning and quality of life decline and where the efficacy of continued treatment is open to both medical and ethical question. Yet, as illness becomes more debilitating, clinical interventions often become more frequent. Studies show that the average Medicare beneficiary with one or more chronic conditions sees eight different

physicians each year. It is at this stage when the medicalization of health care tends to overtake and overwhelm the needs and wishes of patients themselves. Advanced illness, due to disease, chronic conditions, or disability, can happen to anyone at any age. However, the vast majority of people with advanced illness are older than age 65. <http://ppar.oxfordjournals.org/content/24/3/79.extract>

The articles in this issue of the *Public Policy & Aging Report*...

present new ways of understanding the vagaries of advanced illness and the decision-making dilemmas it presents. The issue includes articles on specific programs, demonstrations, and tools that family members and providers can use in providing care to persons with advanced illness, for example:

'Campaign to end unwanted medical treatment.'

'What patients and their families think about unwanted medical treatment.'

Journal contents page:

<http://ppar.oxfordjournals.org/content/24/3.toc>

Two decades of British newspaper coverage regarding do-not-attempt-cardiopulmonary-resuscitation decisions: Lessons for clinicians

RESUSCITATION | Online – 29 October 2014 – 331 articles were identified, resulting from 77 identifiable incidents. The periods 2000-2001 and 2011-2013 encompassed the majority of articles. There were 16 high-profile legal cases, 9 of which resulted in newspaper articles. Approximately 35% of newspaper reports referred to do not attempt cardiopulmonary resuscitation [DNACPR] decisions apparently made without adequate patient and/or family consultation. "Ageism" was referred to in 9% of articles (mostly printed 2000-2002); and, "discrimination against the disabled" in 8% (mostly from 2010-2012). Only five newspaper articles (2%) discussed patients receiving CPR against their wishes. Eighteen newspaper reports (5%) associated DNACPR decisions with active euthanasia. Regarding DNACPR decision-making, the predominant theme was perceived lack of patient involvement, and, more recently, lack of surrogate involvement. Negative language is common, and especially when decisions were presumed unilateral. [http://www.resuscitationjournal.com/article/S0300-9572\(14\)00780-1/abstract](http://www.resuscitationjournal.com/article/S0300-9572(14)00780-1/abstract)

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *ADVANCES IN PSYCHIATRIC TREATMENT*, 2014;20(6):378-379. **'Keeping sight of the fundamental issues.'** Assisting another person's suicide is a criminal offence in England & Wales, although the offence is rare and the law allows for charges not to be brought where there has been no criminal intent. Campaigners for "assisted dying" want something else – a law licensing assisted suicide in advance for certain groups of people in certain circumstances. The present law has been challenged in the courts, hitherto unsuccessfully, as incompatible with article 8 of the European Convention on Human Rights. The Supreme Court has taken the view that, given its social policy implications, this is a matter that Parliament is better placed to consider than the courts. <http://apt.rcpsych.org/content/20/6/378.abstract>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/10/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

ALBERTA HOSPICE PALLIATIVE CARE ASSOCIATION: <http://ahpca.ca/> (Scroll down to 'Media Watch')

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

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://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>

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