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

Decision-making process in end-of-life care: Scroll down to <u>Specialist Publications</u> and 'The impact of the Rasouli decision: A survey of Canadian intensivists' (p.9), in *Journal of Medical Ethics*.

Canada

Let palliative care enough time to prove itself

THE NATIONAL POST | Online Commentary - 3 December 2015 - There is only one form of medical treatment that can accurately be described as "medical aid in dying," and that is palliative care (PC). Which is why PC doctors, as well as many family physicians in Quebec, were almost as appalled by the wording of the bill as they are by euthanasia itself. At a fundraising dinner organized last year by Quebec's Coalition of Physicians for Social justice, a frail and ailing, but still passionate, Dr. Balfour Mount, the father of the PC movement in Canada, called the euphemism "medical aid in dying" a "cowardly distortion of language." The dying, he said, do not want to be killed. They want an "easy death" and "that is what PC gives them." Euthanasia vs. PC is not really a fair fight. We have nothing more to learn about efficient ways to kill people. But PC is a movement that, medically speaking, is still young, still on a learning curve. Eventually, if enough resources become available, as they should, PC will be available to everyone (up to now, limited resources have meant it is usually restricted to terminal cancer patients). Pain control will become more sophisticated and reliable than it is now for hard cases. We have not, in short, given PC a chance to prove itself. When it has achieved all that it can, legal euthanasia may

still be desirable to some Canadians, but I predict the moral panic now driving the demand for legalized euthanasia would melt away. But, I also predict that if euthanasia becomes a norm, it will be motivation to improve and extend PC that melts away. That would be a shame for the overwhelming majority of Canadians who prefer an easeful death to a being killed. Why declare a winner before the game has been played on a level field?

http://news.nationalpost.com/full-comment/barbara-kay-let-palliative-care-enough-time-to-prove-itself

U.S.A.

'Aid-in-dying laws only accentuate need for palliative care, providers say' (p.5), in Kaiser Health News.

Specialist Publications

'The global champion for end-of-life care: Who are you? What is keeping you?' (p.8), in Cancer Nursing.

Efficient, yes, but where is the heart in home care?

THE GLOBE & MAIL | Online - 30 November 2015 - The Victorian Order of Nurses (VON) was, for more than a century, the primary provider of home and community-based care in Canada. Now it is teetering on the verge of bankruptcy. Late last week, the VON shut down operations in six provinces - Alberta, Saskatchewan, Manitoba, New Brunswick, Prince Edward Island, and Newfoundland & Labrador and filed for protection under the Companies' Creditors Arrangement Act. It will continue to operate in Ontario and Nova Scotia - at least for now. The collapse of the iconic organization, founded in 1897 by Lady Aberdeen, was swift and brutal. It serves as a cautionary tale about Canadians' tortured relationship with medicare, in particular the conflicting desires to cling to our

history of charitable provision of care and achieving efficiencies with unforgiving business models. http://www.theglobeandmail.com/globe-debate/efficient-yes-but-where-is-the-heart-in-home-care/article27535617/

Extract from The Globe & Mail article

The real tragedy in VON's unravelling is not that another home-care business is biting the dust (after all, there are hundreds more out there) – but that the "old-fashioned" way of delivering care – taking the time required to talk and listen to patients and treating them as people, not as "units of service" ... is falling by the wayside.

Related:

- ONTARIO | The Toronto Star 4 December 2015 'It's time to finally fix Ontario home-care: Editorial.' What's infuriating isn't simply the revelation that disabled and elderly Ontarians languish far longer than necessary on waiting lists for home-care. Or that those with the same needs get radically different levels of support, depending on where they happen to live. Or that there are no provincial standards specifying the service that people should receive. What's truly maddening is that every one of these problems was indentified five years ago by Jim McCarter, then Ontario's auditor general. Changes were promised. Yet precisely the same home-care failures persist today, hurting some of the province's most vulnerable people. http://www.thestar.com/opinion/editorials/2015/12/04/its-time-to-finally-fix-ontario-home-care-editorial.html
 - '2010 Annual Report' (see Chapter 3.04, Home Care Services), Office of the Auditor General of Ontario, December 2010. [Noted in Media Watch, 13 December 2010, #179 (p.2)] http://www.auditor.on.ca/en/reports en/en10/2010ar en.pdf
- ONTARIO | CTV News 2 December 2015 'Ontario auditor general finds lengthy delays for home-care assessment.' Many elderly and disabled Ontarians are not getting much-needed home-care services on time, with some waiting more than a year just for assessments, the government watchdog says. The level of home-care services that Community Care Access Centres (CCAC) provide vary widely across the province, as each CCAC develops its own criteria as a result of funding inequities, Auditor General Bonnie Lysyk said in her annual report. Her office audited three CCAC and found that 65% of initial assessments for home care were not done within the required time frames. http://www.ctvnews.ca/canada/ontario-auditor-general-finds-lengthy-delays-for-home-care-assessment-1.2683333
 - '2015 Annual Report' (see Chapter 3.1, Community Care Access Centres) Office of the Auditor General of Ontario, December 2015. http://www.auditor.on.ca/en/reports 2015 en.htm [See 'Community Care Access Centres Financial Operations & Service Delivery,' Office of the Auditor General of Ontario, September 2015: http://www.auditor.on.ca/en/reports en.pdf]

Media Watch: Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | Global TV News (Edmonton) 4 December 2015 'Alberta physicians group amends physician-assisted dying document.' The College of Physicians & Surgeons of Alberta approved a new advice document to help doctors once physician-assisted suicide becomes legal in Canada. The college created the document in September, then asked for feedback from the public. A few hundred responses have since shaped amendments to the draft, which include the sections on "competent adult patients" and the "period of reflection." The old document restricted consent to competent adult patients, but that has been amended to include mature minors. The document states, "legal precedent recognizes mature minors as adults in their ability to consent; the college recommends physicians take a careful and conservative approach to mature minors." https://globalnews.ca/news/2380937/alberta-physicians-group-amends-physician-assisted-dying-document/
- THE GLOBE & MAIL | Online 3 December 2015 'Attorney-General seeks extension on assisted-dying deadline.' The Supreme Court of Canada must decide if it will grant a six-month extension to the federal government to respond to its landmark ruling on doctor-assisted death. The federal government's request for a delay has been backed by Nova Scotia, Prince Edward Island, Manitoba, Ontario and Saskatchewan... http://www.theglobeandmail.com/news/politics/attorney-general-seeks-extension-on-assisted-dying-deadline/article27583357/
- QUEBEC | CBC News 2 December 2015 'Federal right-to-die laws will draw "inspiration" from Quebec, PM's spokesman says.' The federal government will draw "inspiration" from Quebec's legislation on doctor-assisted death as it drafts new federal laws around the emotionally charged issue, says a spokesman for the prime minister. Olivier Duchesneau said Prime Minister Justin Trudeau appreciates the "incredible work" done by Quebec's National Assembly on the sensitive issue, and praised Quebec parliamentarians for putting partisanship aside to reach consensus. On Tuesday [of this week], Quebec Superior Court Justice Michel Pinsonnault ruled that Quebec's law allowing some terminally ill patients to end their lives with medical assistance contradicts Criminal Code provisions that remain in place until 6 February 2016. The Quebec government announced it would appeal the Superior Court decision. The province's end-of-life law was set to take effect 10 December. http://www.cbc.ca/news/politics/doctor-assisted-death-legislation-trudeau-1.3346960
- QUEBEC | The National Post 2 December 2015 "We're not expecting hordes of patients": Quebec health minister on historic bill to legalize euthanasia.' The National Post's Graeme Hamilton spoke to Quebec Health Minister Gaétan Barrette Monday [of this week] about Quebec's historic Act Respecting End-of-life Care. The day after the interview, a Quebec Superior Court judge ruled that Quebec's legalization of euthanasia ... is, at least temporarily, in conflict with the federal Criminal Code. http://news.nationalpost.com/news/canada/quebec-health-minister-on-historic-bill-to-legalize-euthanasia
- QUEBEC | CBC News 1 December 2015 'Quebec end-of-life law contradicts Criminal Code and can't take effect, court savs.' A Quebec Superior Court justice has ruled a provincial law allowing some terminally ill patients to end their lives with medical help cannot take effect on 10 December as planned. Justice Michel Pinsonnault said key articles in the new law contradict provisions of Canada's Criminal Code on medically assisted suicide - provisions that are still the law of the land until February 2016. The question of the legality of Quebec's medically assisted dying law, which was passed unanimously in Quebec's National Assembly in June 2014, was brought to the Quebec Superior Court by Paul Saba, the of the Quebec Coalition of Physicians for Social Justice, and Lisa D'Amico, a woman living with life-threatening disabilities. They sought an injunction to contest the provincial law. Justice Pinsonnault did not, in fact, grant that injunction... Pinsonnault instead ruled that the provincial law must be in line with federal laws, which take precedence, and since those have not yet been changed to reflect the Supreme Court ruling on assisted-suicide, the Quebec law cannot take effect. It was the federal attorney general, who was an interlocutor on the case, who raised the question of whether federal law must take precedence over provincial law until the necessary Criminal Code amendments are made. http://www.cbc.ca/news/canada/montreal/guebec-end-of-lifecare-1.3345572

U.S.A.

Who are America's caregivers? Nearly a quarter are millennials

CALIFORNIA | The Tampa Bay Times - 3 December 2015 - Caring for older relatives is usually a task associated with Baby Boomers, the 50- and 60-somethings who find their aging parents need assistance. But almost a quarter of the adults who take care of older people - on top of their regular jobs and other responsibilities — are between the ages of 18 and 34, according to research by the American Association of Retired Persons Policy Institute and the National Alliance for Caregiving. As millions of Americans are expected to live longer than they used to - often losing the ability to do so independently - their families and communities are grappling with how best way to take care of them. The issue has started getting more attention from policy makers. A number of bills pending in Congress could alleviate some of the pressures caregivers face, for instance offering Social Security credits for people who have to take care of their relatives, said Kathleen Kelly, executive director of the Family Caregiver Alliance, a non-profit advocacy organization. These credits would help people who had to drop out of the workforce to take care of a family member preserve their contribution to Social Security retirement benefits. The Institute of Medicine is also putting out a report next year on the state of family caregiving, and a number of states have passed or are considering legislation that would help hospitals better communicate with and train an older person's caregiver, especially after a hospitalization. http://www.tampabay.com/news/health/whoare-americas-caregivers-nearly-a-quarter-are-millennials/2256358

Family vs. hospital: Nevada court addressing issues of life support at end-of-life

NEVADA | *Tyler Morning Telegraph* (Tyler, Texas) – 3 December 2015 – A father's bid to keep his 20-year-old daughter on life-support at a Reno hospital after doctors declared her brain-dead is pending before a Nevada state court judge. Beyond the family attorney's claim that the cost of caring for Aden Hailu is driving hospital efforts to pull the plug, the case raises key questions about Nevada's interpretation of national end-of-life guidelines. What's the issue? The Nevada Supreme Court wants to know whether Saint Mary's Regional Medical Center met state law when doctors declared Aden Hailu dead 28 May 2015, several weeks after she failed to regain consciousness following abdominal surgery. Washoe County Family Court Judge Frances Doherty is revisiting the case because the state high court ruled she was too quick to reject Hailu's family's request to keep Hailu on life-support. Justices say they want evidence that American Association of Neurology guidelines used by the hospital to determine Hailu's brain had ceased to function met "accepted medical standards," as required by state law. The judge has scheduled additional hearings... http://www.tylerpaper.com/TP-News+National/227827/family-vs-hospital-nevada-court-addressing-issues-of-life-support-at-endoflife

Noted in Media Watch, 2 November 2015, #434 (p.7):

- NEVADA | *The Las Vegas Review-Journal* 25 October 2015 '**How Nevada deals with end-of-life spending.**' Federal statistics show legions of Nevadans ... go all-out in the last few months of life, taking desperate medical measures even though death is unavoidable. In the process, patients, their families, their providers and even the medical system suffer immense financial and emotional costs. From hospital invoices that run in the six figures to guilt that can last a lifetime, the final bill is in every way the costliest of all. Nevada, and Las Vegas in particular, have end-of-life spending issues. In Nevada, 19.6% of residents spent seven or more days in intensive care in the last six months of life in 2012, well above the national average of 14.7%, according to the Dartmouth Atlas of Health Care.¹ http://www.reviewjournal.com/news/death-las-vegas/how-nevada-deals-end-life-spending
 - 'Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness,' A
 Report of the Dartmouth Atlas Project, Dartmouth Institute for Health Policy & Clinical Practice, Hanover, New Hampshire, 12 April 2011. [Noted in Media Watch, 18 April 2011, #197 (p.3)]
 http://www.dartmouthatlas.org/downloads/reports/EOL Trend Report 0411.pdf

Aid-in-dying laws only accentuate need for palliative care, providers say

CALIFORNIA | Kaiser Health News - 1 December 2015 - Weeks after California Governor Jerry Brown signed the "end-of-life option act" into law, palliative care (PC) physicians ... are trying to come to terms with what it means for them and their terminally ill patients. It's not just a question of whether they support aid-in-dying or personally would ever help end a life. PC doctors say the law underscores the need to raise awareness among doctors and patients about what they do and to expand access to high-quality programs. Contrary to some patients' fears, they say, PC doctors are not there to hasten death. Their job is to help seriously ill people get relief from symptoms and stress and to improve quality of life for them and their families, regardless of how long the patients have to live. The California law should be a "wakeup" call because it shows "how terrified patients are of what they will experience at the end of life," said Dr. R. Sean Morrison, professor of geriatrics and palliative medicine at Mt. Sinai's Icahn School of Medicine in New York. Morrison said that once patients who want to hasten their death get their symptoms controlled and their spiritual needs addressed, the overwhelming majority want to keep living. "Their choice shouldn't be an assisted death or living with intractable suffering," Morrison said. "That's what laws allowing assisted suicide, in the absence of PC, present as a choice to patients." PC has become more widespread in recent years, and more doctors, nurses and social workers are being trained in how to provide it. In addition, recent legislation in California requires that Medi-Cal [the California Medical Assistance Program] managed care plans ensure access to programs. But gaps remain. A recent report by the California HealthCare Foundation showed that residents in 22 of 58 California counties don't have access to community-based palliative care, and those in 19 counties don't have access to in-patient programs. Foundation researchers also found recently that specialists are in short supply and that there is no reliable way to pay for such care. http://khn.org/news/aid-in-dying-laws-only-accentuate-need-for-palliativecare-providers-say/

 'Dying in California: A Status Report on End-of-Life Care,' California HealthCare Foundation and the Coalition for Compassionate Care, October 2015. [Noted in Media Watch, 26 October 2015, #433 (p.2)] http://www.chcf.org/publications/2015/10/dying-calif-status-report

Related:

• THE GERO JOURNAL | Online – Accessed 30 November 2015 – 'Hospice and palliative care at end of life.' Hospice care and palliative care (PC) are often confused. While there is a component of PC within the hospice care model, there are distinct differences. Hospice is care that encompasses the whole person by emphasizing quality of life through pain and symptom management. Patients who enter hospice are diagnosed with a terminal illness with six or fewer month's life expectancy and are no longer seeking curative treatments. In contrast, PC medicine is a much broader model of care. While pain and symptom treatment is also emphasized in this model, patients can be receiving other appropriate medical care simultaneously. There has been much research on how both hospice and PC can be improved for older adults that may have a terminal illness. Strategies include a larger focus on patient dignity and better communication between family members and care staff. Promoting education for non-cancer terminal patients with dementia is another area that could be improved upon as well as preparing patients and their families of impending death. Hospitals could expand the number of available beds dedicated to hospice patients which has the benefit of overall costs. https://www.gerojournal.com/hospice-and-palliative-care-at-end-of-life/

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

Medicare end-of-life spending declines with age

FORBES | Online – 30 November 2015 – A new Congressional Budget Office working paper has good news about Medicare: end-of-life health care spending declines as seniors grow older. Lest this appear intuitively obvious, let me remind you of another finding from the same study: Medicare spending per beneficiary rises dramatically with age. Average Medicare spending in 2012 was less than \$3,000 per 65-year-old, steadily rising to a peak of nearly \$14,000 for 97-year-olds. After that, it actually declines. So if Medicare spending for the average 97-year-old is roughly 5 times as much as for 65-year-olds, one might well reason that spending in the last years of life likewise might well be five times as higher for those in the 95-105 age group compared to those 65-75. But that is exactly what the researchers did not find. Instead of spending at the end of life being 5 or 4 or even 3 times as high for the oldest group of beneficiaries compared to the youngest, it turns out that the youngest group had spending in their last year of life that was roughly double that of the oldest. http://www.forbes.com/sites/theapothecary/2015/11/30/goodnews-medicare-end-of-life-spending-declines-with-age/

 'Changes in Medicare Spending per Beneficiary by Age,' Working Paper, Congressional Budget Office, Washington DC, November 2015. https://www.cbo.gov/publication/51027

International

End-of-life care in Ireland

Death and bereavement not just a family issue when it comes to our civil servants

IRELAND | *The Independent* (Dublin) – 4 December 2015 – There are almost 30,000 civil servants in Ireland today. They represent a cross section of Irish society. They are the wheels of government. A silent people who do their best to ensure the workings of State. There are almost 30,000 civil servants in Ireland today. They represent a cross section of Irish society. They are the wheels of government. A silent people who do their best to ensure the workings of State. This is why the report I have written, 'Finite Lives – Part 1 – A Report on How the Civil Service Deals with Dying, Death and Bereavement Among its Own Members', is unique. It invited civil servants to talk and share their thoughts and to do so anonymously around their working lives across such a realistic theme. I had never thought of dying, death and bereavement politically. It was, for me, a family issue. However, throughout my time as a senator, I have learned from great educators and leaders in this field that end of life and bereavement extend to nonhealth and into areas of public policy, financial, legal, social, cultural, educational and administrative. I believe it must be at the centre of all Government policy. It is the one life event that Government can plan for, as it is the common ground on which we all stand. https://www.independent.ie/opinion/comment/death-and-bereavement-not-just-a-family-issue-when-it-comes-to-our-civil-servants-34258075.html

1. The report was prepared by Independent Senator Marie Louise O'Donnell following an initiative by Taoiseach (Head of the Irish Government) Enda Kenny. http://www.merrionstreet.ie/en/News-Room/Releases/Taoiseach Enda Kenny launches major report on how the Civil Service deals with dying death and bereavement among its own staff.html

Related:

■ IRELAND | The Irish Times (Dublin) – 4 December 2015 – 'Grieving employees have no legal right to time off for bereavement.' In what it describes as a conservative estimate, the Irish Hospice Foundation says at least one in 10 of the Irish workforce is directly affected by bereavement annually. Yet little legislation or guidance is in place for dealing with grief in the workplace. As a result, someone trying to cope with an unexpected loss may have little or no idea of their rights. http://www.irishtimes.com/business/work/grieving-employees-have-no-legal-right-to-time-off-for-bereavement-1.2453118

China's bereaved elderly protest outside ministry over pensions

CHINA | Radio Free Asia (Washington, DC) – 1 December 2015 – Nearly 1,000 elderly people whose only children have died gathered outside the Ministry for Health & Family Planning in Beijing in protest over a lack of government support, blaming their poverty on draconian one-child population controls which lasted 35 years. The protesters want China's parliament, the National People's Congress to enshrine their right to state welfare provision into a legislative amendment raising the nationwide birth limit to two children per couple. http://www.rfa.org/english/news/china/china-pensions-12012015141110.html

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

New guidance aims to improve end-of-life care for people with autism

U.K. | The Guardian - 1 December 2015 - The British Institute of Learning Disabilities will [soon] launch 'Peaceful, pain free and dignified: Palliative and end-of-life-care for people on the autism spectrum.' Its autism-specific focus and stepby-step descriptions of how health and social care staff can offer better care is timely: in early 2016, health and social care regulator the Care Quality Commission will publish findings on what clinical commissioning group areas are doing to identify end-of-life care as a priority for all groups of people with particular needs, including learning disabilities. There are an estimated 700,000 people with autism and around 1.5 million learning disabled people in the U.K., but the real figure, including the undiagnosed, may be higher. http://www.theguardian.com/society/2015/dec/01 /autism-learning-disability-end-of-life-care

Specialist Publications

'A Delphi study on staff bereavement training in the intellectual and developmental disabilities field' (p.14), in *Intellectual & Developmental Disabili*ties.

'Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ?' (p.13), in Research in Developmental Disabilities.

'Peaceful, Pain Free and Dignified: Palliative and End-of-Life-Care for People on the Autism Spectrum:
 A Guide for Social Care Practitioners,' British Institute of Learning Disabilities, December 2015.
 http://www.bild.org.uk/our-services/books/books-understanding-autism/peaceful-painfree-and-dignified/

Public health funerals in the U.K.

"Paupers' funerals" cost councils £1.7 million

U.K. | BBC News – 30 November 2015 – The cost to local councils of so-called "paupers' funerals" has risen almost 30% to £1.7 million in the past four years. The number of these funerals has risen by 11%, a Freedom of Information request by BBC Local Radio revealed. Public health funerals ... are carried out by local authorities for people who die alone or without relatives able to pay. 436 councils in the U.K. were asked questions about how many public health funerals they carry out and how much these cost them. Of the 409 who are responsible for public health funerals, 300 gave full responses. The results show councils carried out 2,580 public health funerals in 12 months spanning 2013-2014, which represents a small fraction of the 500,000 or so people who die in the U.K. each year. http://www.bbc.com/news/uk-34943805

Noted in Media Watch, 4 April 2015, #404 (p.5):

U.K. | The Daily Mirror – 29 March 2015 – 'Too poor to die – the shocking story of families who can't afford to bury their loved ones.' Figures show an incredible 305,840 applications were made for funeral payments in Great Britain over the past five years. Of those almost 160,000 were accepted as soaring funeral costs leave hard-pressed families dependent on the local council to bury their loved ones. http://www.mirror.co.uk/news/uk-news/poor-die---shocking-story-5419973

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

"Doctors shouldn't underestimate the power that they have"

New Zealand doctors on the care of the dying patient

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 3 December 2015 – With an aging population, the provision of end-of-life care will increase in general practice. There is no doubt that hospice and specialist palliative care (PC) have transformed the quality of care for the dying and their families in New Zealand. However, while respondents in this study seemed realistic about what PC can and cannot achieve, patients and their families may have unrealistic expectations of both hospice and palliative medicine. Many GPs appear confused over the legality of the assistance they provide to the terminally ill, concerned that actions such as increasing medication to address refractory symptoms, or stopping food and fluids may put them at risk of legal censure when they foresee that their actions may hasten death. http://ajh.sagepub.com/content/early/2015/11/25/1049909115619906.abstract

The global champion for end-of-life care: Who are you? What is keeping you?

CANCER NURSING, 2016;39(1):1-2. The interest in a global approach to end-of-life care is reflected in position statements from a number of international organizations and professional associations and in the priority care or research lists generated by small groups involving a limited number of individuals from 3 or more countries. But this level of interest and effort has not become a global initiative, program, or movement. There are no international laws that include end-of-life care as part of a healthcare system, and there are no tested international clinical guidelines, and no globally approved best practices. Of most concern, there may be no political will to legislate the right of all persons to the highest-quality end-of-life care. But what would a global champion do? What would be better for individuals dying a cancer death, their families, and their governments? A global champion would commit to establishing a unified and worldwide plan that would include a shared vision, conceptual model and business plan, consensus priorities for care and the corresponding research and quality improvement strategies, and a common lexicon for use in administration, policy setting, education, care, research, and quality improvement efforts. http://journals.lww.com/cancernursingonline/Fulltext/2016/01000/The Global Champion for End of Life Care Who Are.1.aspx

Parental decision-making on utilisation of out-of-home respite in children's palliative care: Findings of qualitative case study research – a proposed new model

CHILD: CARE, HEALTH & DEVELOPMENT | Online – 7 November 2015 – Respite is an essential element of children's palliative care (PC). Utilisation of out-of-home respite is heavily dependent on a number of interlinked and intertwined factors. The proposed model offers an opportunity to identify how these decisions are made and may ultimately assist in identifying the elements of responsive and family-focused respite that are important to families of children with life-limiting conditions. Each family [i.e., study participant] reported vastly different needs and experiences of respite from their own unique perspective. Cross-case comparison showed for all parents utilising respite care, regardless of their child's age and condition, home was the location of choice. Many interlinking factors influencing these decisions included: past experience of in-patient care, and trust and confidence in care providers. Issues were raised regarding the impact of care provision in the home on family life, siblings and the concept of home. http://onlinelibrary.wiley.com/doi/10.1111/cch.12300/full

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Media Watch: Back Issues

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: http://www.ipcrc.net/archive-global-palliative-care-news.php

Related:

- JOURNAL OF PALLIATIVE MEDICINE | Online 30 November 2015 'Perceptions of the pediatric hospice experience among English- and Spanish-speaking families.' Study participants described the importance of honest, direct communication by medical providers, and anxieties surrounding the expectation of the moment of death. Both [study] groups invoked themes of caregiver appraisal, but English-speaking caregivers more commonly discussed themes of financial hardship and fear of insurance loss, while Spanish-speakers focused on difficulties of bedside caregiving and geographic separation from family. http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0137
- JOURNAL OF PEDIATRIC NURSING | Online 27 November 2015 'Death rituals reported by White, Black, and Hispanic parents following the ICU death of an infant or child.' Rituals after child death require decisions about the child's remains, wakes, funerals/burials at time of great pain for parents. This is especially true for newly immigrated parents and those with language barriers where making arrangements is especially hard and often very isolating. Health professionals who provide support need to be cognizant of practice differences based on religion, culture, economics, family traditions, and individual preference and provide as much support and resource as possible. A list of religious leaders representing the community's cultures and funeral service providers who may provide lower cost burials/cremations is helpful. http://www.pediatricnursing.org/article/S0882-5963(15)00338-3/abstract

A systematic literature review toward the characterization of comfort

HOLISTIC NURSING PRACTICE, 2016;30(1):14-24. Comfort integrates the taxonomies and the classifications of nursing knowledge. Its meaning is not yet clear, although it is an important construct from which theories are developed. This article aims to analyze comfort in nursing scientific literature. Results highlight a particular interest in comfort at crisis situations such as illness, palliative care or intensive care. Comforting seems to be a complex intervention. More studies are needed to achieve its operational assimilation and implementation in clinical practice, as well as the evaluation of its efficiency and effectiveness. http://journals.lww.com/hnpjournal/Abstract/2016/01000/A Systematic Literature Review Toward the.4.aspx

Cuthbertson vs. Rasouli

The impact of the Rasouli decision: A survey of Canadian intensivists

JOURNAL OF MEDICAL ETHICS | Online – 30 November 2015 – In a landmark 2013 decision, the Supreme Court of Canada (SCC) ruled that the withdrawal of life support in certain circumstances is a treatment requiring patient or substitute decision maker (SDM) consent. How intensive care unit (ICU) physicians perceive this ruling is unknown. The authors surveyed intensivists at university hospitals across Canada. Although most respondents reported no change in practice, there was a significant overall shift towards higher intensity and less subjectively appropriate management after the SCC decision. Attitudes to the SCC decision and approaches to disputes over end-of-life (EoL) care in the ICU were highly variable. There were no significant differences among predefined sub-groups. Many Canadian ICU physicians report providing a higher intensity of treatment, and less subjectively appropriate treatment, in situations of dispute over EoL care after the Supreme Court of Canada's ruling in *Cuthbertson vs. Rasouli*. http://jme.bmj.com/content/early/2015/11/30/medethics-2015-102856.abstract

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Updated 12.01.2015

Prison Hospice Backgrounder

End-of-life care – or the lack of – in the prison system has been highlighted on a regular basis in Media Watch. An updated compilation of the articles, reports, etc., noted in past issues of the weekly report is available on the Palliative Care Community Network website at: http://www.pcn-e.com/community/pg/pages/view/3389845/additional-offerings

Noted in Media Watch, 22 June 2015, #415 (pp.10-11):

HEALTH LAW IN CANADA, 2015;35(4):106-119. 'What the Supreme Court didn't say about end-of-life treatment decisions.' When the Supreme Court of Canada released its judgment in Cuthbertson vs. Rasouli, dismissing the physicians' appeal, it was a relief to Mr. Rasouli's family, but a disappointment to many. The judgment, while limited to the facts of this particular case, was not perceived to provide many guidelines for physicians as to how intractable end-of-life disputes could be resolved. It seemed the Supreme Court said that every time a substitute decision-maker insisted "everything be done" to continue the patient's life, the treatment team would either have to comply or make an application to court or (in Ontario) to the Consent & Capacity Board, challenging that demand. Some health practitioners wondered whether the judgment meant that they had to provide treatments they deemed futile, unethical, or in breach of the standard of care for as long as the patient's family demanded. file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/87XQHXCX/Health-Law-in-Canada-May-2015.pdf

N.B. Selected articles on the *Cuthbertson v. Rasouli* case noted in past issues of Media Watch are listed in the weekly report of 15 December 2014, #388 (pp.1-2).

Related:

■ BMC MEDICAL ETHICS | Online — 1 December 2015 — 'Determinants of acceptance of end-of-life interventions: A comparison between withdrawing life-prolonging treatment and euthanasia in Austria.' The representative survey data showed that higher education and stronger socio-cultural liberal orientations increased the likelihood of approving of both withdrawing of life-prolonging treatment and euthanasia, whereas personal experience with end-of-life care increased the likelihood of approval of the former only, and religiosity decreased the approval of euthanasia only. In conclusion, this study found evidence for both the same (education, liberalism) and different (religiosity, care experiences) determinants for the acceptance of withdrawing life-prolonging treatment and euthanasia. http://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-015-0076-y#Sec11

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

Are hospice admission practices associated with hospice enrollment for older African Americans and Whites?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 2 December 2015 – Non-profit hospices and those with larger budgets reported less restrictive admission practices. Hospices with less restrictive admission practices served a larger proportion of patients in both racial groups. However, in the multivariate models, non-profit ownership and larger budgets, but not admission practices, predicted the outcome. Hospices with larger budgets served a greater proportion of African Americans and Whites in their service area. Although larger hospices reported less restrictive admission practices, they also may have provided other services that may be important to patients regardless of race, such as more in-home support or assistance with nonmedical expenses, and participated in more outreach activities increasing their visibility and referral base. http://www.ipsmjournal.com/article/S0885-3924(15)00638-7/abstract

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Media Watch: Palliative Care Network-e Website

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

End-of-life care in France

Do social factors affect the place of death? Analysis of home versus institutional death over 20 years

JOURNAL OF PUBLIC HEALTH | Online – 26 November 2015 – Understanding determinants of place of death is important for public health policy aimed at improving the quality of end-of-life care. In this study, the place of death varied according to time period, demographic factors (age and gender), marital status, and causes of death. Individuals with higher levels of education died more frequently at home. No clear link was found between place of death and social class. However, the self-employed and farmers were more likely to die at home. Although people in France often prefer to die at home, most people do not. The chances that they were able to die where they preferred seem to vary according to socio economic position. The home deaths are coincident with social and educational resources, as well as lifestyle and family solidarity. http://jpubhealth.oxfordjournals.org/content/early/2015/11/25/pubmed.fdv167.abstract

N.B. France was ranked 10th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL ARAFIL20151006 0002.pdf

Related:

■ BMJ SUPPORTIVE & PALLIATIVE CARE | Online - 1 December 2015 - 'Transferring patients home to die: What is the potential population in U.K. critical care units?' Most people when asked, express a preference to die at home, but little is known about whether this is an option for critically ill patients. A retrospective cohort study was undertaken to describe the size and characteristics of the critical care population who could potentially be transferred home to die if they expressed such a wish. A little over 20% of patients dying in critical care demonstrate potential to be transferred home to die. Staff should actively consider the practice of transferring home as an option for care at end of life for these patients. http://spcare.bmj.com/content/early/2015/12/01/bmjspcare-2014-000834.abstract

End-of-life care in Nigeria

Ethics of palliative care in late-stage cancer management and end-of-life issues in a depressed economy

NIGERIAN JOURNAL OF CLINICAL PRACTICE, 2015;18(7):15-19. The Hippocratic Oath has often been referred to as the ethical foundation of medical practice with the key restriction "cause no harm," which is also the principle of benevolence in bioethics. In medical profession, the Oath still exemplifies the key virtues of a doctor in its emphasis on the obligations toward the well-being of the individual patient. In management of end-stage cancer in a depressed economy such as Nigeria, we frequently encounter a wide range of ethical issues that arise in the provision of palliative care (PC) mostly due to the prevailing economic situation and cultural setting. Since most of these patients came from a lower economic class of the society, with little or no formal education and lived at a subsistence level, they often find it difficult to provide the medications needed. In a poor setting where health inequity is rife, and ignorance and poverty are commonplace, a good understanding of medical ethics with a good model of health care system will contribute to the health professional's decision-making that will be in the best interest of the patients. Physicians must protect the lives of their patients and should never hasten their death. In end-stage cancer management, we have to relieve suffering and pains, promote PC, and give psychological support but never abandoning the patient or initiate terminating their life. This presentation is a clinical analysis of the ethical issues regarding the management of end-stage cancer patients in a poor economy with a critical overview of end-of-life issues in African perspective. http://www.njcponline.com/article.asp?issn=1119-3077;year=2015;volume=18;issue=7;spage=15;epage=19;aulast=Chukwuneke

Noted in Media Watch, 1 July 2013, #312 (p.5):

NIGERIA | The Nigerian Observer – 16 August 2013 – 'Perils of operating palliative care in Nigeria.' In a country of about 160 million people, 36 States and 774 Local Government Areas, access to palliative care (PC) is disheartening. There are only two centres – the Palliative Care Initiative (in Ibadan) and Hospice Nigeria (in Lagos). http://www.modernghana.com/news/471174/1/perils-of-operating-palliative-care-in-nigeria.html

Noted in Media Watch, 17 October 2011, #223 (p.2):

- NIGERIA | The Tribune (Ibadan) 14 October 2011 'Experts identify lapses in health care delivery in Nigeria.' Dr. Israel Kolawole, of the University of Ilorin Teaching Hospital, has criticised the nation's health care system, saying the relief of suffering as a goal of medical care has been subjugated or lost ... "our healthcare package does not fully address the emotional, spiritual and psychology suffering faced by patients with life-threatening illnesses." http://www.tribune.com.ng/index.php/community-news/29644-experts-identify-lapses-in-health-care-delivery-in-nigeria
- NIGERIA | The Tribune (Ibadan) 12 October 2011 'Experts canvass support for people living with life-threatening diseases.' The Hospice & Palliative Care Association of Nigeria has decried the unavailability of oral morphine and other opioids, the mainstay drug for pain control in people living with life-limiting or life-threatening illnesses, for example, cancer, kidney failure, AIDS and heart failure. http://www.tribune.com.ng/index.php/community-news/29523-experts-canvass-support-for-people-living-with-life-threatening-diseases

N.B. Nigeria was ranked 77th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [Noted in Media Watch, 16 November 2015, #436 (p.8)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL ARAFIL20151006 0002.pdf

Media Watch: Editorial Practice

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

Distribution

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- **4.** If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
- 5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Use of palliative care services in a tertiary cancer center

THE ONCOLOGIST | Online – 27 November 2015 – In response to accumulating evidence on the benefits of palliative care (PC) referral to oncology patients, efforts are being made to increase PC use. This study, conducted at MD Anderson Cancer Center [Houston, Texas], demonstrates consistent annual growth in PC referrals, which was accompanied by a significant increase in the outpatient referral of patients with non-advanced cancer and earlier referral of those with advanced cancer. In the inpatient setting, the authors found approximate doubling of the inpatient consultations as a percentage of hospital admissions and the ratio of inpatient consultations to hospital beds. In the outpatient setting, they observed variations in referral pattern between oncology services, but, overall, the time from consultation to death/last follow-up increased from 4.8 months to 7.9 months, which was accompanied by a significant decrease in the interval to consultation from hospital registration and advanced cancer diagnosis. However, significant variations in the referral patterns between oncology services were observed. file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/I1673N6U/The%20Oncologist-2015-Dalal-theoncologist.2015-0234.pdf

Related:

JOURNAL OF PALLIATIVE MEDICINE | Online – 30 November 2015 – 'The costs of waiting: Implications of the timing of palliative care consultation among a cohort of decedents at a comprehensive cancer center.' Early palliative care (PC) is associated with less intensive medical care, improved quality outcomes, and cost savings at the end of life for patients with cancer. Despite recommendations that early PC be offered to all patients with metastatic cancer, PC services remain underutilized. http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0119

Noted in Media Watch, 30 November 2015, #438 (p.13)]:

■ NATURE REVIEWS CLINICAL ONCOLOGY | Online – 24 November 2015 – 'Integrating palliative care into the trajectory of cancer care.' Findings from multiple studies indicate integrating PC early in the disease trajectory can result in improvements in quality of life, symptom control, patient and caregiver satisfaction, illness understanding, quality of end-of-life care, survival, and costs of care. The authors discuss strategies to integrate oncology and PC by optimizing clinical infrastructures, processes, education, and research. They provide a conceptual model for the integration of supportive and/or PC with primary and oncological care. The authors discuss how health-care systems and institutions need to tailor integration based on their resources, size, and the level of primary PC available. <a href="http://scholar.google.ca/scholar_url?url=http://www.nature.com/nrclinonc/journal/vaop/ncurrent/full/nrclinonc.2015.201.html&hl=en&sa=X&scisig=AAGBfm3upYv85MX9CAT4ALyEEqNF07yW0g&nossl=1&oi=scholaralrt

Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ?

RESEARCH IN DEVELOPMENTAL DISABILITIES, 2016;49-50:47-59. Adults with intellectual disability (ID) are thought to understand less about death than the general population but there is no available research demonstrating this. Further, the detail of any possible differences in understanding is unknown. The authors compared the responses of 39 adults with mild or moderate ID and 40 disability staff (representing the general population) on 1) Understanding the concept of death; 2) Knowledge of and self-determination about end-of-life planning; and 3) Fear-of-death. They found that adults with ID had a significantly poorer understanding of the concept of death, knew much less about and were less self-determined about end-of-life planning, but reported greater fear-of-death. The authors demonstrated, for the first time, the feasibility of assessing end-of-life planning and fear-of-death among adults with ID. http://www.sciencedirect.com/science/article/pii/S089142221530010X

Related:

INTELLECTUAL & DEVELOPMENTAL DISABILITIES, 2015;53(6):394-405. 'A Delphi study on staff bereavement training in the intellectual and developmental disabilities field.' The Delphi technique was conducted with a panel of 18 experts from formal and informal disability caregiving, nursing, and hospice and bereavement service provision. Results showed that training should help staff identify and support service users experiencing grief. Importantly, staff also needs help in managing their own grief. Organizational policies and resources should be instituted to support the grief processes of both service users and staff. Practice-based applications are discussed, and research implications are presented for training evaluation. http://www.aaiddjournals.org/doi/abs/10.1352/1934-9556-53.6.394

N.B. Articles on the palliative or end-of-life care needs of individuals with intellectual and developmental disabilities have been noted in several issues of Media Watch, for example, the issues of the weekly report of 2 February 2015, #395 (pp.10-11); 29 September 2014, #377 (pp.13-14); 2 June 2014, #360 (pp.10-11); and, 10 March 2014, #348 (pp.8-9).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ EUROPEAN HUMAN RIGHTS LAW REVIEW, 2015;3:285-295. 'The blanket ban on assisted suicide: Between moral paternalism and utilitarian justice.' This article analyses ramifications of the Supreme Court's 2014 Nicklinson judgment. It argues the majority approach to a declaration of incompatibility as judicial incursion into legislative territory does not rest convincingly on the distribution of power envisaged by the Human Rights Act. Contrasting the domestic courts' wider prerogatives to develop human rights with the self-restraint of the Strasbourg Court, driven by the margin of appreciation, the author contends the judgment fails to protect the right to personal autonomy. Unlike the Strasbourg Court, reserved in matters pertaining to the sensitive field of bioethics, where no European consensus can legitimise progressive judgments, domestic courts have more leeway to signal to the legislature that the manner in which discretion was exercised does not strike a fair balance between competing interests. A development in this direction would find support in the general Strasbourg approach to blanket bans in other controversial areas. http://papers.ssrn.com/sol3/papers.cfm?abstract_id=2694087

Noted in Media Watch, 16 June 2014, #362 (p.13):

- ANTHROPOLOGY TODAY, 2014;30(3):14-17. 'The death of the right-to-die campaigners.' The "right-to-die" ... debate in the U.K. has been dominated by high-profile litigation which has brought to public attention stories of individual suffering. The most recent case is that of Tony Nicklinson who, as a result of his permanent and total paralysis which he said made his life "intolerable," wanted the courts to allow a doctor to end his life. Six days after a Judicial Review refused Nicklinson's request, Tony died of "natural" causes. This article compares the presentation by the media of his requested death with his actual death and discusses what this reveals more generally about the way in which the right-to-die debate is presented to the public. http://onlinelibrary.wiley.com/doi/10.1111/1467-8322.12110/abstract;jsessionid=E71FDE73EF70E77A05D31804AE36BF3C.f02t02?deniedAccessCustomisedMessage=&userlsAuthenticated=false
- JOURNAL OF PASTORAL CARE & COUNSELING, 2015;69(4):215-221. 'Physician-assisted suicide and other forms of euthanasia in Islamic spiritual care.' The muteness in the Qur'an about suicide due to intolerable pain and a firm opposition to suicide in the hadith literature formed a strong opinion among Muslims that neither repentance nor the suffering of the person can remove the sin of suicide or mercy "killing" (al-qatl al-rahim), even if these acts are committed with the purpose of relieving suffering and pain. Some interpretations of the Islamic sources even give advantage to murderers as opposed to people who commit suicide because the murderers, at least, may have opportunity to repent for their sin. However, people who commit suicide are "labeled" for losing faith in the afterlife without a chance to repent for their act. This paper claims that Islamic spiritual care can help people make decisions that may impact patients, family members, health care givers and the whole community by responding to questions such as "What is the Islamic view on death?", "What is the Islamic response to physician-assisted suicide and other forms of euthanasia?", "What are the religious and moral underpinnings of these responses in Islam?" http://pcc.sagepub.com/content/69/4/215.abstract

SOUTH AFRICAN JOURNAL OF BIOETHICS & LAW, 2015;8(2):34-40. 'Stransham-Ford v. Minister of Justice & Correctional Services and Others: Can active voluntary euthanasia and doctorassisted suicide be legally justified and are they consistent with the biomedical ethical principles? Some suggested guidelines for doctors to consider.' The case of Stransham-Ford v. Minister of Justice & Correctional Services and Others held voluntary active euthanasia and doctor-assisted suicide may be legally justified in certain circumstances. The court observed the distinction between "active" and "passive" voluntary euthanasia is not legally tenable as, in both instances, the doctors concerned have the "actual" or "eventual" intention to terminate the patient's life and have caused or hastened the patient's death. It is argued as the South African Constitution is the supreme law of the country, the fundamental rights of patients guaranteed in the Constitution cannot be undermined by ethical duties imposed on healthcare practitioners by international and national professional bodies. The court ... did not use ethical theories and principles to decide the matter. It simply applied the values in the Constitution and the provisions of the Bill of Rights. However, in order to assist medical practitioners with practical guidelines with which many of them are familiar - rather than complicated unfamiliar philosophical arguments – the biomedical ethical principles of patient autonomy, beneficence, non-maleficence and justice or fairness are applied to active voluntary euthanasia and doctor-assisted suicide in the context of the Stransham-Ford case. Although the case has not set a precedent or opened the floodgates to doctor-assisted voluntary active euthanasia and it is open to Parliament, the Constitutional Court or other courts to develop the concept or outlaw it, some guidelines are offered for doctors to consider should they be authorised by a court to assist with voluntary active euthanasia. file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/I1673N6U/446-2522-1-PB.pdf

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-jahpc/publications/newsletter/2015/11/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]

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: http://www.eapcnet.eu/Themes/Organization/Links.aspx [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

 $HUNGARY \mid Hungarian \ Hospice \ Foundation: \ \underline{http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes}$

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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