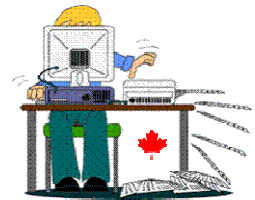


Media Watch...

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.

15 June 2015 Edition | Issue #414



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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to [Specialist Publications](#) and 'Meanings of at-homeness at end of life among older people' (p.16), in *Scandinavian Journal of Caring Sciences*.

Canada

Multi-centre Canadian-U.S. study

When will you die? New stats tool claims to know

CTV NEWS | Online – 8 June 2015 – A new statistical tool can accurately predict your chances of dying within one year of being admitted to hospital, according to a Canadian-led team of researchers.¹ The University of Ottawa's Dr. Carl van Walraven and his team of researchers say they can predict any patient's chances of dying within one year of a hospital admission, using only commonly-collected medical data and a newly-developed scoring system called the Hospital-patient One-year Mortality Risk (HOMR). The HOMR tool was found to accurately predict that 8.7% of patients died within one year of being admitted to hospitals in Ontario, Alberta and Boston over an eight-year period, using data gathered from more than 3 million patients during that time. It factored in a wide range of variables, in-

cluding demographics, reason for admission, deadliness of the illness and the patient's living situation at home. The HOMR tool proved to be accurate to within 0.3%...
<http://www.ctvnews.ca/health/when-will-you-die-new-stats-tool-claims-to-know-1.2411854>

Specialist Publications

'What diagnostic tools exist for the early identification of palliative care patients in general practice? A systematic review,' (p.14), in *Journal of Palliative Care*.

'Communication and quality of care on palliative care units: A qualitative study' (p.14), in *Journal of Palliative Medicine*.

1. 'External validation of the Hospital-patient One-year Mortality Risk (HOMR) model for predicting death within 1 year after hospital admission,' *Canadian Medical Association Journal*, 8 June 2015. <http://www.cmaj.ca/content/early/2015/06/08/cmaj.150209.full.pdf+html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 5 June 2015 – ‘**Canadian Catholics divided on assisted suicide ruling as bishops ask to be consulted on any new law.**’ Canadian Catholic organizations have been sharply divided by the legalization of assisted suicide, with bishops asking to be consulted on any new law – and critics urging no “collaboration” on what they call an immoral hastened-death scheme they say the church should have no part of. <http://news.nationalpost.com/news/religion/canadian-catholics-divided-on-assisted-suicide>

U.S.A.

Quality-of-life care may help cancer patients live longer, feel better

CALIFORNIA | *The Los Angeles Times* – 12 June 2015 – There are 14 million cancer survivors in the U.S., according to the American Cancer Society... As treatments improve and more people are diagnosed at earlier stages, cancer survivors are living longer, prompting a paradigm shift from merely living to living well. And it turns out some factors that improve quality of life may also increase survival. A 2013 study¹ ... compared late-stage lung cancer patients who received standard oncology care with those who also received palliative care (symptom management, psychosocial support and help with decision making) soon after diagnosis. Patients in the palliative care group not only reported improvements in mood and quality of life, but they also received less aggressive end-of-life care and lived 30% longer than those who received only standard care. “You’d expect there would be a quality-for-quantity trade-off,” says Dr. Daniel Stone, medical director of Cedars-Sinai Medical Group, who was not involved in the study. “But the conclusion was that palliative care makes you feel better and helps you live longer.” Stone adds that it’s unknown whether the survival advantage came from the positive benefits of psychological support or whether forgoing additional chemo at the end of life made a difference. But, he says, “having someone [on your team] whose orientation is focused on alleviating symptoms is very helpful.” <http://www.latimes.com/health/la-he-wellness-cancer-20150613-story.html>

1. ‘Early palliative care in advanced lung cancer: A qualitative study,’ *JAMA Internal Medicine*, 28 January 2013 [Noted in *Media Watch*, 4 February 2013, #291 (p.8)] <http://archinte.jamanetwork.com/article.aspx?articleid=1566605>



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>

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.17.

End-of-life counsel from doctors seen as lacking

MASSACHUSETTS | *The Boston Globe* – 9 June 2015 – Americans routinely tell researchers they don't want to spend their final days tethered to machines in a hospital, preferring to die at home with less invasive treatments. But that rarely happens. Now, a study from Brigham & Women's Hospital suggests the biggest reason for that disconnect appears to be the doctors who treat those patients.¹ The physicians, the study suggests, have outsized influence in shaping how patients spend their final days. That has profound implications not just for patients but for medical care more broadly, with end-of-life care accounting for a staggering share of all medical spending. "For so many patients, no one has ever sat down with them and talked with them about hospice care, instead of being on a ventilator or in a nursing home," said the study's lead researcher, Dr. Ziad Obermeyer, an assistant professor of emergency medicine and health care policy at Harvard Medical School. "As physicians, we need to have these conversations earlier." To reach their conclusion, Brigham researchers scoured the medical records of thousands of terminally ill cancer patients nationwide. Those whose physicians frequently refer patients to hospice are 27% more likely to spend their final days in that type of end-of-life care. <http://www.bostonglobe.com/metro/2015/06/08/doctors-play-pivotal-role-determining-end-life-decisions-brigham-study-finds/vlkw2Cb5urAtgguvp7n7QL/story.html>

1. 'Physician characteristics strongly predict patient enrolment in hospice,' *Health Affairs*, 2015; 34(6):993-1000. <http://content.healthaffairs.org/content/34/6/993.abstract?sid=0dd67719-a795-44d6-a606-fdaf58482d9c>

Bipartisan bill to improve planning options for patients with advanced illness

WASHINGTON DC | *The Augusta Free Press* (Virginia) – 10 June 2015 – U.S. Senators Mark R. Warner (Democrat-Virginia) and Johnny Isakson (Republic-Georgia) introduced legislation designed to give people with serious illness the freedom to make more informed choices about their care, and the power to have those choices honored. The Care Planning Act of 2015 creates a Medicare benefit for patient-centered care planning for people with serious illness. It will reimburse a team of healthcare professionals for providing a voluntary, structured discussion about the patient's goals, illness, and treatment options. Under this legislation, a written plan would reflect the informed choices made by patients in consultation with their health care team, faith leaders, family members and friends. The Act also provides resources for public and professional education materials about care planning. <http://augustafreepress.com/warner-isakson-introduce-bipartisan-bill-to-improve-planning-options-for-patients-with-advanced-illness/>

Specialist Publications

'Do physicians have a responsibility to provide recommendations regarding goals of care to surrogates of dying patients in the ICU? YES' (p.12), in *Chest*.

'Do physicians have a responsibility to provide recommendations regarding goals of care to surrogates of dying patients in the ICU? No' (p.12), in *Chest*.

'Future demand for long-term care workers will be influenced by demographic and utilization changes' (p.12), in *Health Affairs*.

'Who rules home care? The impact of privatization on profitability, cost, and quality' (p.13), in *Home Health Care Management & Practice*.

Noted in Media Watch, 30 March 2015, #403 (p.7):

- REUTERS | Online – 23 March 2015 – ‘**Reimburse doctors for helping patients plan end-of-life care, experts say.**’ Physician incentives are needed to improve end-of-life care in the U.S., health experts said at an Institute of Medicine (IOM) forum convened to discuss action on the recommendations of the Institute’s seminal fall [2014] report...¹ When people fail to plan for end-of-life care, they may suffer through ultimately futile, invasive and often unwanted treatments. <http://www.reuters.com/article/2015/03/23/us-end-of-life-care-reimbursement-idUSKBN0MJ2E920150323>

1. ‘Dying in America: Improving Quality & Honoring Individual Preferences Near the End of Life,’ IOM, 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/~media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf>

International

Elder Care in New Zealand

Aged home use double previous estimate

NEW ZEALAND | TVNZ News (Auckland) – 12 June 2015 – Nearly twice as many New Zealanders as previously thought end up in retirement homes and public debate is needed about how to keep funding the system, researchers say.¹ In the first-ever study about how common residential aged care is in the country, researchers from the University of Auckland have found about 47% of all people over 65 will live in a retirement home at some point. That number is also expected to rise to about 53% by 2040, the paper said. Its authors said the huge shift in estimates would have a particular impact on the way residential aged care would be funded in the future. <http://tvnz.co.nz/national-news/aged-home-use-double-previous-estimate-6336874>

1. ‘Likelihood of residential aged care use in later life: a simple approach to estimation with international comparison,’ *Australian & New Zealand Journal of Public Health*, 11 June 2015. <http://onlinelibrary.wiley.com/doi/10.1111/1753-6405.12374/abstract>

End-of-life care in Indonesia

A defining moment

INDONESIA | *The Jakarta Post* – 10 June 2015 – Palliative care is a work in progress in Indonesia. A newly launched three-year project to improve palliative care in Jakarta aims to change that. Enhancing Palliative Care Practice, launched in January this year by the Singapore International Foundation, is jointly conducted with the Indonesia Cancer Foundation in Jakarta and the non-profit organization the Rachel House, which has provided free palliative care for terminally ill poor children in Indonesia since it was first set up in 2006. As part of the program, Singapore’s palliative care specialists, led by Singapore International Volunteers team leader Ramaswamy Akhileswaran, will partner with medical professionals in Indonesia from ten hospitals in Jakarta to improve care for terminally ill patients. <http://www.thejakartapost.com/news/2015/06/10/a-defining-moment.html>

Major study finds early palliative care for cancer patients costs a lot less

IRELAND | *The Journal* (Dublin) – 9 June 2015 – Trinity College Dublin has teamed up with Mount Sinai in New York to publish new research that shows that giving advanced cancer patients early palliative care is not only better for the health of the patient, but significantly lowers costs for the health system.¹ While previous research has shown the clinical benefits, this new

Cont.

study shows how it also results in significant cost reductions of up to 24%. The intervention reduced both the length and intensity of hospital stay for patients with advanced cancer. This is the first time that a study into the economic benefits of early palliative care intervention has been carried out. They found that an intervention within six days was estimated to reduce costs by 14% compared to no intervention. An intervention within two days led to a 24% reduction in cost of hospital stay. <http://www.thejournal.ie/trinity-college-cancer-research-2150352-Jun2015/>

1. 'Prospective cohort study of hospital palliative care teams for inpatients with advanced cancer: Earlier consultation is associated with larger cost-saving...' *Journal of Clinical Oncology*, 8 June 2015. <http://jco.ascopubs.org/content/early/2015/06/08/JCO.2014.60.2334.abstract?sid=8eeb2a9a-2c82-4c44-977e-20379484e230>

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

End-of-life care in New Zealand

Call for changes to Māori palliative care

NEW ZEALAND | New Zealand Radio News – 9 June 2015 – Some academics are calling for more rigorous training to ensure Māori receive better care at the end of their lives. They say the current palliative care system does not do enough to cater to the cultural needs of Māori. University of Auckland Professor Merryn Gott and her colleague Tess Moeke-Maxwell have spent the past five years researching end-of-life care for Māori and how it could be improved. Professor Gott said, when it came to palliative care in Aotearoa, a one-size-fits-all approach was not effective. She said the current hospice model was based on Western culture. "There's actually a philosophy that underpins [it] and it's quite a Western philosophy about what good death looks like. Certainly there are some dissonances between that and what Māori would want for themselves at the end of life," she said. "So I think there's a real need to understand the different, culturally nuanced needs of Māori at the end of life and to look at how services could be optimised to support those." Ms. Gott said Māori have special tikanga, or customs, around death that Western cultures do not understand because they don't have them themselves. <http://www.radionz.co.nz/news/te-manu-korihi/275826/call-for-changes-to-maori-palliative-care>

Noted in Media Watch, 10 December 2014, #386 (p.11):

- *MAI JOURNAL*, 2014;3(2):140-152. '**End-of-life care and Māori whānau resilience.**' This article focuses on the cultural resources that made Māori carers resilient when providing care to an ill family member at the end of life. Caring often took place against a backdrop of poverty, personal factors, racism and a lack of health literacy affecting access to resources. http://www.journal.mai.ac.nz/sites/default/files/MAI_Jrnl_V3_iss2_Maxwell.pdf

N.B. Whānau means the extended family, family group, a familiar term of address to a number of people – in the modern context the term is sometimes used to include friends who may not have any kinship ties to other members. Additional articles on Māori beliefs and practices in the context of end-of-life care are noted in Media Watch, 16 June 2014, #362 (p.8) and 17 March 2014, #349 (p.9).

[Media Watch posted on Palliative Care Network-e Website](#)

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

End-of-life care in Africa

Iris House provides free, community-based care for special needs children

SOUTH AFRICA | All Africa – 9 June 2015 – South Africa's first Children's Hospice & Palliative Care Association will be launched later this year, according to the founder of Iris House Children's Hospice Sue van der Linde. Van der Linde has for the past decade been instrumental in lobbying for improved legislation around the rights of children with special needs in South Africa. She said that while Iris House – the only children's hospice of its kind in the country – was affiliated to the Hospice & Palliative Care Association, the association is not spe-

cifically for children with special needs and cannot provide the necessary oversight. <http://allafrica.com/stories/201506091793.html>

Specialist Publications

'The prioritisation of paediatrics and palliative care in cancer control plans in Africa' (p.9), in *British Journal of Cancer*.

Too poor to die: How funeral poverty is surging in the U.K.

U.K. | *The Guardian* – 9 June 2015 – The sharp rise in funeral poverty is one of the grimmer trends in our unequal island: in the past decade, funeral costs have risen by 80%. Wages simply haven't. The average funeral now costs £3,163 nationally, and £4,836 in London. If you're on a low income, the cost of a sudden death is far beyond your modest means, and life insurance can seem like an unnecessary luxury when you're struggling to heat your home and feed your children. <http://www.theguardian.com/commentisfree/2015/jun/09/poor-die-funeral-poverty-costs-uk>

Noted in Media Watch, 6 April 2015, #404 (p.5):

- U.K. | *The Mirror* – 29 March 2015 – **'Too poor to die – the shocking story of families who can't afford to bury their loved ones.'** New 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>

Report: A profile of the care at home sector in Scotland 2015

U.K. (Scotland) | Care Appointments – 9 June 2015 – A new academic report commissioned by Scottish Care¹ ... was launched ... at Scottish Care's annual National Care At Home & Housing Support Conference... Delivering care and support to people in their own homes, helping them to retain their independence and community connectedness, and preventing unnecessary admission to hospital or long-term care, are central to the Scottish Government's strategy for reshaping care and improving outcomes for adults and older people with care needs. The hope is it will focus attention on the sector, highlight key challenges, and stimulate discussion about future development. If care at home is to fulfil its full potential, there needs to be a collective commitment and nationally endorsed plan of action. <http://www.careappointments.co.uk/practice-reports/item/37400-report-a-profile-of-the-care-at-home-sector-in-scotland-2015>

1. 'Home Delivery: A profile of the care at home sector in Scotland 2015, Scottish Care, June 2015. http://scottishcare.org/docs/037_280_schomedeliveryreport2015_1433756203.pdf

Dying man left in pain for “significant period” in final hours of life and had to wait three hours to be seen by a doctor

U.K. (Wales) | Wales Online – 9 June 2015 – A dying man receiving end-of-life care was denied the chance to die with dignity and had to wait three hours to be seen by a doctor, according to a damning report. The Public Services Ombudsman’s report into the failings by Hywel Dda University Health Board and the Welsh Ambulance Service said the man from Pembrokeshire was experiencing pain and anxiety for a “significant period” in the final hours of his life. Health bosses failed to ensure that adequate out-of-hours GP cover was in place in the area on July 15, 2013. There had also been a failure to ensure the man had access to adequate pain relief over the weekend period before his death. The man, named only as Mr X, was diagnosed with idiopathic pulmonary fibrosis. Having been discharged from hospital he had returned home for end-of-life palliative care. But the investigation found that the health board failed to provide reasonable care for him, and to ensure that he remained comfortable and pain free in the final days of his life. <http://www.walesonline.co.uk/news/health/dying-man-left-pain-significant-9414090>

Terminal care lagging in Finland – health workers insufficiently trained

FINLAND | Uutiset – 8 June 2015 – Finnish palliative care is well behind other European countries, with doctors and nurses receiving inadequate training for treating terminally ill patients. However, interest in developing palliative care is slowly rising. Patients who are living out the final months, weeks or even days of their lives do not receive adequate care or attention... Many terminally ill people suffer from fears and pains that healthcare workers aren’t able to help them face. “The biggest obstacle seems to be the healthcare professional’s ability to come face to face with the patient and their families,” says Juha Hänninen, of the Terhokoti terminal care home in Helsinki. “Painkillers are also often administered too carefully.” The reason for the distress of some of those terminally ill has to do with the low level of training doctors and nurses receive for situations involving dying patients. Many doctors may dismiss the final needs of the terminally ill. http://yle.fi/uutiset/terminal_care_lagging_in_finland_health_workers_insufficiently_trained/8056140

Noted in Media Watch, 12 March 2015, #244 (p.5):

- FINLAND | YLE News – 11 March 2012 – ‘**Doctors want terminal care written into law.**’ Specialist doctors are calling for legislation that would mandate the provision of end-of-life care throughout Finland. They want a strong push in this direction as recommendations from the Ministry of Social Affairs & Health have failed to bring tangible results in public health services. http://www.yle.fi/uutiset/news/2012/03/doctors_want_terminal_care_written_into_law_3324094.html

New study on extended family to ensure care

SINGAPORE | *The Straits Times* – 8 June 2015 – With families in Singapore shrinking, can a wider network of relatives be relied on to help if someone becomes frail or ill? That is what the Government is trying to find out, with what is believed to be its first study on the extended family, and the extent of care and support it can provide. The data ... may then be used for policy tweaks to encourage people to support their aunts, uncles, nephews, nieces, cousins and other relatives. This study ... marks a milestone in social policy thinking, said experts, because it is moving away from the Government’s traditional proxy for families – the nuclear household where a couple live with their parents or children. <http://www.straitstimes.com/news/singapore/more-singapore-stories/story/new-study-extended-family-ensure-care-20150608>

Cont.

Noted in Media Watch, 22 April 2013, #302 (p.12):

- **PALLIATIVE MEDICINE** | Online – 15 April 2013 – ‘**Uncovering an invisible network of direct caregivers at the end of life: A population study.**’ Most palliative care research about caregivers relies on reports from spouses or adult children. Some recent clinical reports have noted the assistance provided by other family members and friends. This population study aims to define the people who actually provide care at the end of life. Extended family members (not first degree relatives) and friends accounted for more than half of identified hands-on caregivers. <http://pmj.sagepub.com/content/early/2013/04/11/0269216313483664.abstract>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GERMANY | *Deutsche Welle* (Bonn) – 9 June 2015 – ‘**German parliament introduces bills on assisted suicide.**’ Germany inched ever closer to joining its neighbor Belgium in allowing active assisted suicide on Tuesday as two new draft bills were presented to the lower house of parliament, the Bundestag, ahead of a debate on the subject in July. <http://www.dw.de/german-parliament-introduces-bills-on-assisted-suicide/a-18505698>
- U.K. | *The Guardian* – 9 June 2015 – ‘**MPs to debate assisted dying legislation.**’ Legislation that would give terminally ill patients the right to die is to be debated by the House... Labour MP Rob Marris, who topped the ballot for private members’ bills, is to adopt draft regulations drawn up by Lord Falconer. The bill proposed by the former lord chancellor and justice secretary ran out of time in the Lords during the last parliament despite gathering significant support. <http://www.theguardian.com/society/2015/jun/09/assisted-dying-mps-debate-legislation-lord-falconer-bill-terminally-ill-right-to-die>

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Please feel free to share this weekly report with your colleagues.
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MW 400: Palliative care in advanced lung disease: The challenge of integrating palliation into everyday care

Download the complete issue (PDF 450 KB) 

CHEST | Online – 5 March 2015 | The tendency toward “either/or” thinking (either cure or comfort) in traditional biomedical care paradigms does little to optimize care in advancing chronic illness. Calls for improved palliation in chronic lung disease mandate a review of related care gaps and current clinical practices. [read more...](#)

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<http://www.ipcrc.net/archive-global-palliative-care-news.php>

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

The prioritisation of paediatrics and palliative care in cancer control plans in Africa

BRITISH JOURNAL OF CANCER | Online – 4 June 2015 – The authors conducted an analysis of accessible national cancer control plans in Africa, using a health systems perspective attentive to context, development, scope, and monitoring/evaluation. Burden estimates were derived from World Bank, World Health Organisation, and Worldwide Palliative Care Alliance. Eighteen national plans and one Africa-wide plan (10 English, 9 French) were accessible, representing 9 low-, 4 lower-middle-, and 5 upper-middle-income settings. Ten plans discussed cancer control in the context of non-communicable diseases. Paediatric cancer was mentioned in 7 national plans, representing 5127 children, or 13% of the estimated continental burden for children aged 0-14 years. Palliative care needs were recognised in 11 national plans, representing 157,490 children, or 24% of the estimated Africa-wide burden for children aged 0-14 years; four plans specified paediatric palliative needs. Palliative care was itemised in 4 budgets. Sample indicators and equity measures were identified, including those highlighting contextual needs for treatment access and completion. Recognising explicit strategies and funding for paediatric and palliative services may guide prioritised cancer control efforts in resource-limited settings. <http://www.nature.com/bjc/journal/vaop/ncurrent/abs/bjc2015158a.html>

Obstacles to the promotion of dialogue between parents, children and health professionals about death and dying in pediatric oncology

INTERNATIONAL ARCHIVES OF MEDICINE, 2015;8(126):1-5. In Brazil, cancer is the second leading cause of death among children and adolescents, forcing family members, patients and professionals to deal with the issues of human finitude. The multidisciplinary team considers the discussions at the end of life as a difficult task to be performed on pediatric patients. The family is essential to overcome the communication barriers, acting as liaison between the multidisciplinary team and the patient. Children should be invited to participate in the decision making process and their wishes should be honored at the end of life. Professionals should be able to meet the physical, psychosocial, spiritual, social and cultural rights of patients and families. <http://imed.pub/ojs/index.php/iam/article/view/1188/844>

N.B. Selected articles on communication in pediatric palliative care listed in past issues of Media Watch are noted in the issue of the weekly report of 6 April 2015, #404 (pp.6-7)

Noted in Media Watch, 7 September 2009, #113 (p.8):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2009;12(11):1015-1021. ‘**The beginnings of children’s palliative care in Africa: Evaluation of a children’s palliative care service in Africa.**’ The study suggests affordable, nurse-led, volunteer-supported children’s palliative care services are both achievable and effective... Such a service would clearly identify children in need of children’s palliative care and should provide medication for symptom control; food and basic needs support; play and learning facilities; child protection; and systems for patient education, communication and follow up. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2009.0125>

The rule of rescue: An investigation into age-related preferences and the imperative to save a life

CLINICAL ETHICS | Online – 5 June 2015 – The dominant rule of economic evaluation within health care posits that resources are distributed in order to maximize health benefit. There are instances, however, where the public has demonstrated that they do not prefer such an allocation scheme, particularly in the context of life-saving interventions. The results [of this study] indicate that saving a life holds value beyond that captured by traditional health benefit measurement and that the value of saving a life is not consistent across ages. More specifically, the value of saving a life was age-dependent and markedly attenuated for older-age patients. Many [questionnaire] respondents were willing to overlook maximizing health benefit in order to rescue a life in immediate

peril, and showed a diminished sense of moral imperative to rescue older-age patients. <http://cet.sagepub.com/content/early/2015/04/14/1477750915588891.abstract>

Extract from the *Clinical Ethics* article:

In light of difficulties related to the implementation of larger-scale policies incorporating rule of rescue concerns, the most realistic approaches will likely involve adopting smaller-scale policies that address issues such as do not resuscitate (DNRs) and living wills. Potential policy solutions such as age or monetary thresholds for life-saving interventions may be favoured in a research context; however, their overall social feasibility is questionable.

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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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.

Unfinished business in bereavement

DEATH STUDIES | Online – 9 June 2015 – Unfinished business (e.g., incomplete, unexpressed or unresolved relationship issues with the deceased) is frequently discussed as a risk factor for chronic and severe grief reactions. This study aimed to address a gap in the literature by examining the presence and severity of unfinished business as well as common themes of unfinished business reported in open-ended qualitative narratives among a sample of 224 bereaved individuals. In analyses, self-reported presence of unfinished business and the severity of distress due to unfinished business were both found to be associated with poorer bereavement outcomes. However, after controlling for potential confounds, distress related to unresolved issues with the deceased emerged as a more robust correlate of these outcomes. Qualitative responses were categorized, and the type of reported unfinished business was not significantly related to the degree of unfinished business distress or other bereavement outcomes. These findings provide preliminary justification for bereavement interventions that aim to ameliorate distress related to unresolved relational issues with the deceased. <http://www.ncbi.nlm.nih.gov/pubmed/26057117>

Noted in Media Watch, 11 August 2014, #370 (p.11):

- *INTERNATIONAL JOURNAL OF PSYCHOTHERAPY*, 2014;18(2):72-79. **'The truth shall set you free: Saying an honest "goodbye" before a loved-one's death.'** This article reviews some of the relevant literature, defines the premise of "unfinished business," describes the therapeutic benefits of fantasy, and provides a case example using the "empty chair" method. <http://www.scottdmiller.com/wp-content/uploads/2014/07/Why-Most-Therapists-are-Average-German-2014.pdf#page=72>

A future care planning initiative to improve the end-of-life care of patients on the complex care ward of a district general hospital

FUTURE HOSPITAL JOURNAL, 2015;2(2): 87-89. Medically led, patient-centred, future care planning for patients predicted to be in their last year of life is possible on the complex care ward of an acute hospital, where patients often wait for social care placement into a nursing home. When the patient lacks the mental capacity to engage in the planning discussions themselves, meetings can take place between the multidisciplinary geriatric team and either those close to the patient or an independent mental capacity advocate. Participants ... should use any existing advance care planning information, as appropriate, to develop "best interests advice" (which can be referred to at a later date when a best interests decision needs to be made for the patient). Any future medical care plan should be reviewed for applicability and validity if the person's condition changes (improves or deteriorates), if the patient or those close to the patient request it, or 6-12 months after the initial plan is made. Education, training and support must be provided to ensure acceptance and understanding of the PErsonalised Advisory Care E process and general end-of-life care. <http://futurehospital.rcpjourn.org/content/2/2/87.full.pdf+html>

The economic evidence for advance care planning: Systematic review of evidence

PALLIATIVE MEDICINE | Online – 9 June 2015 – There are no published cost-effectiveness studies. Included studies focus on healthcare savings, usually associated with reduced demand for hospital care. Advance care planning appears to be associated with healthcare savings for some people in some circumstances, such as people living with dementia in the community, people in nursing homes or in areas with high end-of-life care spending. There is need for clearer articulation of the likely mechanisms by which advance care planning can lead to reduced care costs or improved cost-effectiveness, particularly for people who retain capacity. There is also a need to consider wider costs, including the costs of advance care planning facilitation or interventions and the costs of substitute health, social and informal care. Economic outcomes need to be considered in the context of quality benefits. <http://pmj.sagepub.com/content/early/2015/06/08/0269216315586659.abstract>

Cont.

Of related interest:

- *CHEST*, 2015;147(6):1453-1455. **‘Do physicians have a responsibility to provide recommendations regarding goals of care to surrogates of dying patients in the ICU? YES.’** Approximately 20% of Americans spend time in an ICU around the time of their death, and most deaths follow a decision to limit life-sustaining therapies. Many factors contribute to treatment limitation decisions, including patient prognosis, expected benefits and burdens of available treatments, and patient preferences. Because many patients in the ICU lack decision-making capacity, a surrogate decision-maker often speaks on behalf of the patient and collaborates with the treating physician... <http://journal.publications.chestnet.org/article.aspx?articleid=2300399>
- *CHEST*, 2015;147(6):1455-1457. **‘Do physicians have a responsibility to provide recommendations regarding goals of care to surrogates of dying patients in the ICU? No.’** At first, it seems that physicians might have a responsibility to recommend goals of care for dying patients in the ICU. I suggest this is mistaken. Not only do physicians usually have no such responsibility to recommend goals, it is even a mistake if they do. Usually, the next of kin or other surrogate is the decision-maker in such cases, but regardless of whether it is a still-competent patient or a surrogate, many bad things can happen if physicians try to recommend treatment goals. <http://journal.publications.chestnet.org/article.aspx?articleid=2300400>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 June 2015 – **‘Patient-nurse communication about prognosis and end-of-life care.’** Two hundred seventy-nine nurses registered 1,809 patient conversations [for this study]... Prognosis and end-of-life care were among the least frequently discussed topics, whereas symptoms was discussed most often. Prognosis was discussed with 687 patients (38%), and end-of-life care with 179 patients (10%). Prognosis and end-of-life care were discussed more frequently in The Netherlands than in Sweden... The nurses did not always recognize prognosis and end-of-life care discussions as a part of their professional role. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0037>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 11 June 2015 – **‘Toward a systematic approach to assessment and care planning in palliative care: A practical review of clinical tools.’** Ensuring a consistent and systematic approach to the delivery of care for people with advanced disease is a priority for palliative care services worldwide. Many clinical tools are available to aid in this process; however, they are often used sporadically, and implementation of a routine set of clinical tools to guide care planning in the specialist palliative care sector in Australia has not been achieved. This study sought to recommend key clinical tools that may assist with the assessment and care planning of specialist palliative care provision for patients and family caregivers admitted to specialist palliative care settings (home, hospital, and hospice). Twelve tools with practical relevance were recommended for use across settings of care. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9766991&fulltextType=RA&fileId=S1478951515000565>

Long-term care in the U.S.

Future demand for long-term care workers will be influenced by demographic and utilization changes

HEALTH AFFAIRS, 2015;34(6):936-945. A looming question for policy makers is how growing diversity of the U.S. elderly population and greater use of home and community-based services will affect demand for long-term care workers. The authors used national surveys to analyze current use and staffing of long-term care, project demand for long-term care services and workers through 2030, and assess how projections varied if we changed assumptions about utilization patterns. If current trends continue, the occupations anticipated to grow the most over the period are counselors and social workers (94%), community and social services workers (93%), and home health and personal care aides (88%). If 20% of nursing home care were shifted to home health services, total employment growth would be about 12% lower. Policy makers and educators should redouble efforts to create and sustainably fund programs to recruit, train, and retain long-term care workers. <http://content.healthaffairs.org/content/34/6/936.abstract?sid=0377d8ff-8f51-4ac6-b040-3b37753b1272>

Home care in the U.S.

Who rules home care? The impact of privatization on profitability, cost, and quality

HOME HEALTH CARE MANAGEMENT & PRACTICE | Online – 2 June 2015 – This article explores the literature, including two recent studies, on whether home health agency (HHA) ownership type plays a significant role in agency quality, cost, and profitability. The literature is limited, except for the two recent studies that use a merged database created from the Medicare Home Health Compare and the 2010 Medicare home health cost reports databases. One study found statistically significant differences between proprietary and non-profit HHAs: proprietary agencies have lower overall quality, higher profitability, higher costs per patient, and more visits per patient, with therapy visits accounting for a larger share of the total. However, the second study found that the explanatory value of ownership is limited, with the number of HHAs in the state and therapy visits as a percentage of total visits having a significant influence on cost and quality when combined with ownership compared with ownership alone. Policy, practice, and research implications are discussed. <http://hhc.sagepub.com/content/early/2015/06/01/1084822315588520.abstract>

End-of-life care in France

Symptom assessment for a palliative care approach in people with dementia admitted to acute hospitals: Results from a national audit

JOURNAL OF GERIATRIC PSYCHIATRY & NEUROLOGY | Online – 4 June 2015 – As part of a national audit of dementia care, 660 case notes were reviewed across 35 acute hospitals. Many assessments essential to dementia palliative care were not performed. Seventy-six patients died, were documented to be receiving end-of-life (EOL) care, and/or were referred for specialist palliative care. Even less symptom assessment was performed (e.g., no pain assessment in 27%, no delirium screening in 68%, and no mood or behavioral and psychological symptoms of dementia in 93%). In all, 37% had antipsychotic drugs during their admission and 71% of these received a new prescription in hospital, most commonly for “agitation.” This study suggests a picture of poor symptom assessment and possible inappropriate prescription of antipsychotic medication, including at EOL... <http://jgp.sagepub.com/content/early/2015/06/04/0891988715588835.abstract>

Of related interest:

- *INTERNATIONAL PSYCHOGERIATRICS* | Online – 10 June 2015 – ‘**Achieving consensus and controversy around applicability of palliative care to dementia.**’ On behalf of the European Association for Palliative Care, the authors recently performed a Delphi study to define domains for palliative care in dementia and to provide recommendations for optimal care. An international panel of experts in palliative care, dementia care or both, achieved consensus on almost all domains and recommendations, but the domain concerning the applicability of palliative care to dementia required revision. Some experts expressed concerns about bringing up end-of-life issues prematurely and about relabeling dementia care as palliative care. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9766185&fulltextType=RA&fileId=S1041610215000824>

Noted in Media Watch, 16 February 2015, #397 (p.11):

- *INTERNATIONAL PSYCHOGERIATRICS* | Online – 13 February 2015 – ‘**An evaluation of palliative care contents in national dementia strategies in reference to the European Association for Palliative Care white paper.**’ Although palliative care was not explicitly referred to in eight of the fourteen countries [reviewed], and only to a limited extent in three of these countries, a number of domains from the Association’s white paper were well represented...¹ <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9557793&fulltextType=RA&fileId=S1041610215000150>

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1. 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,' *Palliative Medicine*, published online 4 July 2013. [Noted in Media Watch, 8 July 2013, #313 (p.8)] <http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract>

N.B. Selected articles on end-of-life care for people living with dementia listed in past issues of Media Watch are noted in the issue of the weekly report of 9 February 2015, #396 (p.9).

What diagnostic tools exist for the early identification of palliative care patients in general practice? A systematic review

JOURNAL OF PALLIATIVE CARE, 2015;31(2):118-123. Timely identification of patients who will die in the foreseeable future is essential to providing appropriate care, but such identification is difficult. This study aims to identify evidence-based early identification tools for life limiting illness in the primary care setting, and to describe their core elements. Four diagnostic tools were identified. A narrative process described and compared the identified tools with a focus on practicality in clinical care. The tools identified pave the way for the development of an international, standardized, evidence-based approach to the early identification of palliative patients. <http://www.ingentaconnect.com/content/iug/jpc/2015/00000031/00000002/art00008;jsessionid=3p5r5r1s4sq0j.alexandra>

Communication and quality of care on palliative care units: A qualitative study

JOURNAL OF PALLIATIVE MEDICINE | Online – 12 June 2015 – Clinician-patient communication is central in palliative care, but it has not been described qualitatively which specific elements of communication are important for high-quality palliative care, particularly in the inpatient setting. There were 46 interviews and eight focus groups. Communication was the most prevalent theme regarding satisfaction and quality of care, with five sub-themes describing elements important to patients, caregivers, and staff. These included: 1) building rapport with patients and families to build trust and kinship; 2) addressing expectations and explaining goals of care; 3) keeping patients and families informed about the patient's condition; 4) listening actively to validate patients' concerns and individual needs; and, 5) providing a safe space for conversations about death and dying. Patients, family caregivers, and health care providers affirmed that communication is a central element of quality of care and family satisfaction on PCUs. The five sub-themes identified may serve as a structure for education and for quality improvement tools in palliative care inpatient settings. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0408>

EAPC white paper

Improving practice, attaining outcomes and delivering quality services: Recommendations from the European Association for Palliative Care Task Force on Outcome Measurement

PALLIATIVE MEDICINE | Online – 11 June 2015 – Twelve recommendations are proposed covering key parameters of measures, adequate measures for the task, introduction of outcome measurement into practice, and national and international outcome comparisons and benchmarking. Compared to other recommendations, the white paper covers similar aspects but focuses more on outcome measurement in clinical care and the wider policy impact of implementing outcome measurement in clinical palliative care. Patient-reported outcome measure feedback improves awareness of unmet need and allows professionals to act to address patients' needs. <http://pmj.sagepub.com/content/early/2015/06/11/0269216315589898.abstract>

The palliative care needs of people severely affected by neurodegenerative disorders: A qualitative study

PROGRESS IN PALLIATIVE CARE | Online – 6 June 2015 – Specialist palliative care services are often involved in the care of people with progressive neurological disease, in particular amyotrophic lateral sclerosis. However, the particular needs of people with advanced and progressive neurological disease are not well known. A qualitative approach was used, interviewing people with advanced amyotrophic lateral sclerosis/motor neurone disease, multiple sclerosis, Parkinson's disease, and multiple systems atrophy and their family carers to ascertain their particular needs. People with progressive disease have many, difficult and distressing symptoms: physical, including pain, movement issues, swallowing and speech problems, psychological, feelings of being abandoned and of anxiety and depression, social, of isolation, of being a burden and of financial issues, and spiritual, of loss of hope and the meaning of life as they approach death. <http://www.maneyonline.com/doi/abs/10.1179/1743291X15Y.0000000007>

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

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

N.B. Selected articles on end-of-life care for people living with a neurological condition listed in past issues of Media Watch are noted in the issues of the weekly report of 23 February 2015, #398 (p.15-16) and 30 March 2015, #403 (p.11).

Palliative sedation: Controversies and challenges

PROGRESS IN PALLIATIVE CARE, 2015;23(3):153-162. Palliative sedation (PS) is used increasingly commonly for symptom management in terminally ill patients in the Western world. The main controversies involving PS are whether it is the same as euthanasia, whether the practice supports patient autonomy, whether sufficient safeguards are or could be in place to prevent its abuse and what its spread may mean for the future of palliative care. While other reviews consider them separately, here the legal, scientific, ethical, and pragmatic challenges to the practice are examined together to provide a broad context in which to assess the current state of the practice. <http://www.maneyonline.com/doi/abs/10.1179/1743291X15Y.0000000004>

Noted in Media Watch, 12 May 2014, #357 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – ‘**Palliative sedation: An analysis of international guidelines and position statements.**’ Guidelines were published by the American College of Physicians & American Society of Internal Medicine (2000), the Hospice & Palliative Nurses Association (2003), the American Academy of Hospice & Palliative Medicine (2006), the American Medical Association (2008), the Royal Dutch Medical Association (2009), the European Association for Palliative Care (2009), the National Hospice & Palliative Care Organization (2010), and the National Comprehensive Cancer Network (2012). <http://ajh.sagepub.com/content/early/2014/05/06/1049909114533002.abstract>

Meanings of at-homeness at end-of-life among older people

SCANDINAVIAN JOURNAL OF CARING SCIENCES | Online – 8 June 2015 – Maintaining the well-being of older people who are approaching the end-of-life has been recognised as a significant aspect of well-being in general. However, there are few studies that have explicitly focused on at-homeness among older people. This study aims to illuminate meanings of at-homeness among older people with advancing illnesses. Two aspects of the phenomenon were revealed in this study: 1) at-homeness as being oneself; and, 2) at-homeness as being connected. At-homeness as being oneself meant being able to manage ordinary everyday life as well as being beneficial to one's life. At-homeness as being connected meant being close to significant others, being in affirming friendships and being in safe dependency. Here, at-homeness is seen as a two-fold phenomenon, where being oneself and being connected are interrelated aspects. Being oneself and being connected are further interpreted by means of the concepts of agency and communion, which have been theorised as two main forces of the human being. <http://onlinelibrary.wiley.com/doi/10.1111/scs.12246/abstract>

Of related interest:

- *SAFETY IN HEALTH* | Online – Accessed 17 June 2015 – ‘**Client, caregiver, and provider perspectives of safety in palliative home care: A mixed method design.**’ Palliative care clients with complex needs are increasingly choosing to remain at home for their care. Home represents familiarity, presence of supportive family and friends, potential for normalcy and, a safe haven. The palliative care literature although robust is hardly ever linked with safety and home care. Patient safety has been focused predominantly on institutions without a corresponding level of research or safety initiatives in the home care sector. Although a growing body of research has begun to highlight the complexity and multidimensionality of home care safety there is a dearth of understanding of safety issues from the perspectives of clients, caregivers, and paid providers... <http://www.safetyinhealth.com/content/pdf/2056-5917-1-3.pdf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CONSULTANT PHARMACIST*, 2015;30(6):352-355. ‘**Death with dignity: The developing debate among health care professionals.**’ The right-to-die movement ... remains controversial. Currently, only five states have aid-in-dying laws, but many others have bills under consideration. The legalized process for physician-assisted suicide has a strict set of procedures that physicians and patients must follow to ensure the competency and safety of all parties involved. Opposition against legalizing physician-assisted suicide encompasses more than simply moral, religious, or ethical differences. While some individuals believe that physician-assisted suicide gives patients autonomy in their end-of-life care, health care professionals also may have reservations about the liability of the situation. Pharmacists, in particular, play a pertinent role in the dispensing of, and counselling about, the medications used to assist patients in hastening their death. <http://www.ingentaconnect.com/content/ascp/tcp/2015/00000030/00000006/art00006>
- *JOURNAL OF MEDICAL ETHICS* | Online – 10 June 2015 – ‘**Equal in the presence of death?**’ When life ends, everything ends, at least for those who do not believe in an afterlife, so it is no wonder that decisions about ending life should be taken with as much seriousness and consideration as possible. Most of the worries raised around ending the life of someone with treatment-resistant major depressive disorder seem to be justified. Could depression pass away or be cured with some new drug or therapy that is yet to come? Is his or her wish to die genuine, and not just a part of the disease? Will allowing depressed people to die not cause loss of hope and a cascade of suicides among others suffering from the same condition? However, there are strong reasons for allowing people suffering from untreatable depression to end their lives. The primary reason is the severity of the suffering caused by depression. Many people with depression, and also many doctors and other carers, assess this suffering as worse than most forms of physical suffering. <http://jme.bmj.com/content/early/2015/06/10/medethics-2015-102810.extract>

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- *SOUTH AFRICAN MEDICAL JOURNAL*, 2015;105(6):432-433. ‘**Judge nudges dormant euthanasia draft law.**’ A terminally ill Cape Town advocate who died of natural causes hours before a High Court judge granted him the locally unprecedented right to end his life ... may have speeded up long-recommended progressive law more in line with provisions of the Constitution. <http://www.hmpg.co.za/index.php/samj/article/viewFile/7826/9327>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/06/media-watch/>

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

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

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

Asia

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

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

Australia

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

Canada

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

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to ‘Additional Resources’]

Europe

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

HUNGARY | Hungarian Hospice Foundation: <http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

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

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