

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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Patients at risk of receiving inappropriate end-of-life care: Scroll down to [Specialist Publications](#) and 'The prevalence of medical error related to end-of-life communication in Canadian hospitals: Results of a multicentre observational study' (p.10), in *BMJ Quality & Safety*.

Canada

Look to home care to help aging Saskatchewan population, says analyst

SASKATCHEWAN | CBC News (Saskatoon) – 9 November 2015 – As Saskatchewan's population ages, the demands on the healthcare system grow, and health policy analyst Steven Lewis says we should be looking towards home care to meet those needs. "Most people would prefer not to be in the nursing home," he said on CBC's Saskatoon Morning. "Even the best nursing homes are pretty forbidding places." Lewis said the focus in Canada has historically been on institutional care. Communities thought it was good when they got a new nursing home. But Lewis points to the European system as an example of better social support systems within the home. "In 1989, Denmark actually passed a law that said we're not going to build anymore nursing home beds." He said this was a way of saying they will give people more support in the home. Denmark has a lot of housing options and community-based care. Lewis described Canada's home care system as "spotty." For example, the home care system will cover someone who is sick and then discharged from the hospital, he said, but the frail and elderly don't receive as much attention. <http://www.cbc.ca/news/canada/saskatoon/look-to-home-care-to-help-aging-sask-population-says-analyst-1.3311058>

Noted in Media Watch, 29 April 2013, #303 (p.1):

- SASKATCHEWAN | CJME News (Regina) – 24 April 2013 – '**Keeping elderly out of care homes focus of Saskatchewan government.**' Health Minister Dustin Duncan ... insists Saskatchewan already has more beds *per capita* than most other provinces for people over 70. He says that the way to improve long term care for seniors is by keeping them out of those facilities in the first place. That's why the government is increasing spending on providing assistance to seniors in their own homes. <http://cjme.com/story/keeping-elderly-out-care-homes-focus-sask-government/106879>

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.20.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE TORONTO STAR* | Online – 12 November 2015 – ‘**Ask the Supremes for an extension: Editorial.**’ Less than three months remains before Canada’s longstanding criminalization of assisted suicide becomes null and void. Unless new legislation is hurriedly passed – or the 6 February 2016 deadline is extended – Canadians and their doctors will be forced to make end-of-life decisions in legal limbo. That mustn’t happen. Nor should the newly elected Liberal government rush to deliver legislation... The only responsible option at this point is to formally ask the Supreme Court to extend the deadline for crafting a new law by several more months. Given that parliamentary business was interrupted by the longest election campaign in modern history, and a new government has taken office facing a steep learning curve, it’s hard to imagine the court rejecting a request for more time. The case for delay is even stronger now both Ontario and British Columbia have signalled a postponement would be welcome. <http://www.thestar.com/opinion/editorials/2015/11/12/ask-the-supremes-for-an-extension-editorial.html>

U.S.A.

Path to avoiding unwanted end-of-life medical treatment

MICHIGAN | *The Detroit News* – 13 November 2015 – Nearly 1 in 4 older Americans (24%) say that either they or a family member have experienced excessive or unwanted medical treatment. That’s the equivalent of about 25 million people, according to a poll conducted last year by Purple Strategies.¹ A key reason for this problem is only about 1 in 6 Americans (17 percent) say they’ve had discussions about their end-of-life health care goals, preferences and values with a doctor or other health care provide. Evidence-based research overwhelmingly shows the need for more and higher-quality doctor-patient conversations about the patient’s health care goals, preferences and values. The report “Dying in America” by the Institute of Medicine notes that: “Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care.”² The majority of these patients will receive acute hospital care from physicians who do not know them. As a result, advance care planning is essential to ensure that patients receive care reflecting their values, goals, and preferences.” One important step that should facilitate advance care planning is the Centers for Medicare & Medicaid Services’ recent decision to reimburse doctors for communicating with patients about their preferences and values about end-of-life care. <http://www.detroitnews.com/story/opinion/2015/11/13/grube-end-life-treatment/75755598/>

1. ‘Unwanted Medical Treatment Survey,’ Purple Insights, February 2014. [Noted in Media Watch, 4 August 2014, #369 (p.10)] <https://www.compassionandchoices.org/userfiles/UMT-survey-feb-2014.pdf>
2. ‘Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,’ Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>

Noted in Media Watch, 2 November 2015, #434 (p.4):

- *THE NEW YORK TIMES* | Online – 30 October 2015 – ‘**New Medicare rule authorizes “end-of-life” consultations.**’ Six years after legislation to encourage end-of-life planning touched off a furor ... the Obama administration issued a final rule [effective January 2016] that authorizes Medicare to pay doctors for consultations with patients on how they would like to be cared for as they are dying. http://www.nytimes.com/2015/10/31/us/new-medicare-rule-authorizes-end-of-life-consultations.html?_r=0

Why death should be discussed in school – and how teachers should handle it

THE WASHINGTON POST | Online – 13 November 2015 – How do you explain to hundreds of grade school children a beloved kindergarten teacher with breast cancer is dying? A friend recently asked me for advice as this was happening at her child's school. Both she and the school leadership felt lost. While the situation was tragic, I was glad they wanted to have the conversation. I was glad they were reaching out for help. My friend's request reminded me of when one of my son's kindergarten classmates died of brain cancer. At the time, I asked my son if the teachers talked about his classmate's death. He told me the kids started to talk about it, but the teacher discouraged their conversation. I felt disappointment and concern. I thought teachers would appreciate the importance of allowing children to ask questions and express their feelings. While I talked with my son about his classmate, not all children have someone at home to whom they can turn. As a physician who cares for families of dying children regularly, I am used to having these conversations, but I know most people are not. They may not know how to go about it or know what is appropriate to say, especially with children. These conversations are important. But like life, death is ubiquitous. Most kids will endure the death of a family

member or friend before their 18th birthday. <https://www.washingtonpost.com/news/answer-sheet/wp/2015/11/13/why-death-should-be-discussed-in-school-and-how-teachers-should-handle-it/>

Limestone County case shows gaps in Alabama's end-of-life policies, expert says

ALABAMA | AL.com – 12 November 2015 – Rene Hoover, mother of a terminally-ill special education student in Limestone County, has been waging a public battle to allow her son to attend public school with a do-not-resuscitate order. But if she and her son lived just over the state line in Tennessee it wouldn't be an issue, said Dr. Monica Williams-Murphy, medical director for advanced care planning and end-of-life education at Huntsville Hospital. "The parent of a minor can sign [an order] and say this is in the patient's best interests," Williams-Murphy said. "It would allow paramedics or schools to be covered if the child died at school. In Alabama, we're just behind the national trend." She has been working with lawmakers on creating advanced directives that are portable, and follow patients regardless of where they are being treated. <http://www.al.com/news/index.ssf/2015/11/limestone-county-case-shows-ga.html>

Selected articles on discussing dying and death in the classroom

- HAWAII | KITV 4 News (Honolulu) – 10 February 2015 – **'Iolani School offers hospice course to students.'** As a teacher, Bob Kane began pondering ways he could use the subjects of death and terminal illness to boost the self-esteem of his students. He devised a course where students could be trained in caring for those facing life-limiting illnesses. [Noted in Media Watch, 23 February 2015, #398 (p.4)] <http://www.kitv.com/news/-Iolani-School-offers-hospice-course-to-students/31188258>
- MINNESOTA | *International Falls Daily Journal* – 29 October 2011 – **'The journey from life to death: Students participate in end-of-life simulation.'** After learning about hospice, Rainy River Community College students were given 12 pieces of paper on which they wrote the names of three important people in their lives, three prized possessions, three favorite activities and three attributes about themselves of which they were most proud. After being told they had a life-threatening illness with six months to live, they were given thirty seconds to rip up three pieces of paper, signifying things they had to give up. Later, one-by-one, they had torn up all their papers except two. [Noted in Media Watch, 31 October 2011, #225 (p.3)] http://www.ifallsdailyjournal.com/view/full_story/16198444/article-The-journey-from-life-to-death--Students-participate-in-end-of-life-simulation
- THE NETHERLANDS | TheAge.com.au – 14 February 2007 – **'Lesson in life and death: Pupils build dying teacher's coffin.'** Eri van den Biggelaar has just a few weeks to live after being diagnosed with an aggressive form of cervical cancer. She asked the woodwork teacher to build a coffin for her. "Why don't you let the children make it?" he replied. Now pupils ... have been helping with the finishing touches. "Life and death belong together," van den Biggelaar said. "The children realised that when I explained it to them. I didn't want to be morbid about it; I wanted them to help me. None of the children considered it creepy ... and nobody felt traumatised. Parents of the children involved all gave their consent. [Noted in Media Watch, 8 August 2011, #213 (p.9, under 'Worth Repeating')] <http://www.theage.com.au/news/world/lesson-in-life-and-death-pupils-build-dying-teachers-coffin/2007/02/13/1171128974213.html>

Lessons in end-of-life care from the Veterans Administration

THE NEW YORK TIMES | Online – 11 November 2015 – Several years ago, colleagues and I ... developed a survey that is now used in all Veterans Affairs (VA) hospitals and nursing homes to assess families' perceptions of the care that veterans received at the end of life.¹ The Bereaved Family Survey is sent to families of patients after the patients have died, and asks ... about pain, information, decision making, and emotional and spiritual support... Often the answers to those questions were surprising. For instance, hospitals I thought would have done very well, didn't. And others did much better than I (and they) thought they could have. And I heard many wonderful stories of doctors, nurses and other staff members going out of their way to meet patients' and families needs. Those answers also showed the VA how to improve the care patients and families received. We learned families were more satisfied with their care when a palliative care (PC) consult team saw the pa-

tient. And they were most satisfied when the patient died in a specialized PC unit. These surveys can be extraordinarily valuable in understanding how we're meeting patients' and families' needs, and how we're not. As the Department of Veterans Affairs uses these results to meet the end-of-life needs of our veterans and their families with respect for all they have done for our country, other hospitals also need to ensure dying patients have the care they deserve. <http://opinionator.blogs.nytimes.com/2015/11/11/lessons-in-end-of-life-care-from-the-v-a/>

Specialist Publications

'Impact of staffing on access to palliative care in U.S. hospitals' (p.11), in *Journal of Palliative Medicine*.

1. 'The Bereaved Family Survey,' Center for Health Equity Research & Promotion, U.S. Department of Veterans Affairs. [http://www.cherp.research.va.gov/CHERP/PROMISE/The PROMISE Survey.asp](http://www.cherp.research.va.gov/CHERP/PROMISE/The_PROMISE_Survey.asp)

Noted in Media Watch, 19 October 2015, #432 (p.13):

- *MILITARY MEDICINE*, 2015;180(10):1024-102. '**Palliative care in the U.S. Military Health System.**' Currently, the Military Health System (MHS) has only two palliative (PC) teams across all of its 56 facilities: one at Walter Reed National Military Medical Center and the other at Madigan Army Medical Center. Although the MHS is a leader in trauma and point of injury care, we are lagging far behind the Veterans Health Administration (VHA) and the civilian sector in providing essential PC services to our patients. <http://publications.amsus.org/doi/full/10.7205/MILMED-D-15-00047>

Noted in Media Watch, 2 February 2015, #395 (p.3):

- NATIONAL PUBLIC RADIO | Online – 28 January 2015 – '**Veterans Affairs steps up programs as more veterans enter hospice care.**' Starting last year, more military veterans are passing away in hospice care than in all of Veterans Affairs trauma and ICU wards combined. That's because the millions of Americans who served in Korea [1950-1953] and World War II [1941-1946] are reaching their 80s and 90s; Vietnam veterans are reaching their 70s. That means the U.S. Department of Veterans Affairs is focusing on how to make them comfortable in their final weeks and months. <http://www.npr.org/blogs/health/2015/01/28/381938804/va-steps-up-programs-as-more-veterans-enter-hospice-care>

N.B. As of 2014, there were 19.1 million veterans in the U.S.

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>

All-out care at end of life takes toll in agony, expense – and it’s worse in Dallas

TEXAS | *The Dallas Morning News* – 8 November 2015 – Most medical practitioners argue that surgically inserted feeding tubes for such patients are uncomfortable, alienating and fruitless, requiring restraints and prolonging the course of dying rather than giving the patient more days of a life they would want to live. But when indecision reigns, U.S. health care has a fallback position: Do everything. Feeding tubes for dying Alzheimer’s patients are one example of the high cost of dying. In Dallas, there are many others. Dallas is one of the nation’s most expensive places to die. It is also a city where death is a prolonged process. In the last two years of life, the average Dallas patient spent \$79,515 of Medicare funds, according to federal data for 2012 sifted by the Dartmouth Institute for Health Policy & Clinical Practice.¹ The national average was \$70,686. One in 5 Dallas seniors who died that year died in a hospital – fewer than in years

past. But their bills were well above the national average. And, more spent at least a week in intensive care. America’s spending during the typically years-long decline to death from chronic diseases is four times greater than the amount spent by wealthy European countries, but gives us no more life expectancy. It is one of the key reasons that the cost of care is so high. <http://www.dallasnews.com/business/health-care/20151108-default-of-do-it-all-care-at-end-of-life-takes-toll-in-agony-expense--and-its-worse-in-dallas.ece>

Specialist Publications

‘Responding to requests for potentially inappropriate treatments in intensive care units’ (p.17), in *Annals of the American Thoracic Society*.

1. ‘Tracking Improvement in the Care of Chronically Ill Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life,’ The Dartmouth Institute, 12 June 2013. [Noted in Media Watch, 11 June 2013, #310 (p.4)] http://www.dartmouthatlas.org/downloads/reports/EOL_brief_061213.pdf

Noted in Media Watch, 22 April 2013, #302 (p.2):

- TEXAS | *The Dallas Morning Star* – 19 April 2013 – ‘**Texas Senate approves end-of-life bill.**’ The Senate has approved the first major revisions in the state’s end-of-life law in more than a decade, giving patients and their families new safeguards and tripling the number of days for them to find a new facility when their current provider decides to end treatment. Patients and families will have the right to object to use of a do not attempt resuscitation order and to ask an independent ethics committee to review the case. It also would ensure that pain management and comfort care may not be withheld from a patient at the end of life. <http://www.dallasnews.com/news/politics/state-politics/20130418-texas-senate-approves-end-of-life-bill.ece>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ARIZONA | *The Yuma Sun* – 9 November 2015 – ‘**Poll: Most Arizonans seek ability to end their lives if terminally ill.**’ A majority of Arizonans want the ability to get a prescription allowing them to end their own lives if they are terminally ill, according to a new poll. And the older the person, the greater the desire. The survey of 700 adult heads of households found 63% of those 55 and older support a proposal which would allow a doctor to prescribe a lethal drug to those who physicians conclude are terminally ill and mentally competent. Younger respondents favored the plan by smaller margins. Pollster Earl de Berge of the Behavior Research Center said this is not physician-assisted suicide. It is modeled after a similar law in Oregon which the U.S. Supreme Court upheld nearly a decade ago. That requires the person be physically able to administer the medication, either orally or by injection. http://www.yumasun.com/news/poll-most-arizonans-seek-ability-to-end-their-lives-if/article_37eaf092-8746-11e5-b04d-3f6776c9876c.html

International

End-of-life care in Wales

Wales the “only U.K. country” to provide 24/7 end-of-life care

U.K. (Wales) | ITV News – 13 November 2015 – A new Welsh Government report says Wales is the only country in the U.K. to provide round-the-clock support and advice for people approaching the end of their lives. The Welsh Government says its second annual report about palliative care in Wales also highlights “excellent feedback from patients and their loved ones” about how services are making a difference to people’s lives in their final days. In 2012, the Welsh Government published plans to improve end-of-life care in Wales. Last year, additional spending of £6.4 million was announced to support hospices and provide end-of-life care across the country. <http://www.itv.com/news/wales/2015-11-13/wales-the-only-uk-country-to-provide-24-7-end-of-life-care/>

Extracts from a report on the Welsh government’s end-of-life care delivery plan

Percentage of people dying in hospital has fallen from 62.6% in 2008-2009 to 56.2% in 2014-2015.

15.7% increase in the number of people registered on a primary care palliative register over the last 12 months.

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

Hospices “must take more inclusive approach to ageing Muslims”

U.K. | *The Guardian* – 12 November 2015 – Hospices in the U.K. must meet the challenge of an ageing Muslim population by overcoming barriers that deter Britain’s largest faith minority from using their services, ensuring that language, cultural and religious needs are met. The U.K. hospice network should see a significant increase in Muslim patients in coming years as a result of rising numbers of elderly Muslims combined with changes to traditional family structures, a new report says.¹ But only a handful of more than 200 adult and children’s hospices in the U.K. have Muslim patients, reflecting “a perception that hospices aren’t really for us”, said Sughra Ahmed, programmes manager in the Centre for Policy & Public Education at the Woolf Institute. Unless existing hospices take positive steps to be inclusive, Muslims are likely to set up parallel institutions with implications for social cohesion and integration, said Ahmed. According to the 2011 census, there were 2.7 million Muslims living in the U.K., or almost 4.8% of the population... Although the Muslim community is generally young, with 33% aged 15 or under, 4% were over 65 – with numbers increasing as those who came to the U.K. as young men and women in the 1960s and 1970s grow older. <http://www.theguardian.com/society/2015/nov/12/hospices-must-take-more-inclusive-approach-ageing-muslims>

1. ‘Bridging the Gap: Strengthening Relations Between Hospices & Muslims of Britain,’ The Woolf Institute, for Hospice UK & Together for Short Lives. <http://www.woolf.cam.ac.uk/resources/reports.asp>

Noted in Media Watch, 16 February 2015, #397 (p.10):

- *GLOBAL BIOETHICS* | Online – 9 February 2015 – ‘**Islam and palliative care.**’ While the general ethos of palliative care, which is to promote the quality of life of those facing life-limiting illnesses, is consistent with Islamic values, this paper explores whether the same can be submitted for modern methods of pain control. The investigation will be steered by two overriding questions. First, if pain and suffering could, as highlighted in the primary sources of Islamic Law, lead to the expiation of sins, can pain relief be taken? Second, is it religiously permissible to choose pain treatment options that could bring about iatrogenic addiction, the hastening of death and the impairment or obliteration of consciousness? http://www.tandfonline.com/doi/abs/10.1080/11287462.2015.1008752#.VOCMaebF_YQ

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Noted in Media Watch, 12 January 2015, #392 (p.7):

- *AMERICAN JOURNAL OF BIOETHICS*, 2015;15(1):3-13. **‘Ethical obligations and clinical goals in end-of-life care: Deriving a quality-of-life construct based on the Islamic concept of accountability before God (Taklif).’** End-of-life medical decision making presents a major challenge to patients and physicians alike. In order to determine whether it is ethically justifiable to forgo medical treatment in such scenarios, clinical data must be interpreted alongside patient values, as well as in light of the physician’s ethical commitments. Though much has been written about this ethical issue from religious perspectives (especially Christian and Jewish), little work has been done from an Islamic point of view. <http://www.tandfonline.com/doi/abs/10.1080/15265161.2014.974769>

N.B. This issue of the *American Journal of Bioethics* includes several articles on end-of-life care from the Islamic perspective. Contents page: <http://www.tandfonline.com/toc/uajb20/current>. Additional articles on the subject are noted in Media Watch, 15 December 2014, #388 (pp.11-12), 16 June 2014, #362 (p.11), and 28 March 2011, #194 (p.10).

Related:

- U.K. | *The Guardian* – 13 November 2015 – **‘End-of-life care is a universal right that functions as a white privilege.’** End-of-life care, catapulted into the public eye with the uproar over “death panels,” has since evolved into a nuanced discussion of how we can help people die. One thing that often gets lost in the mix is the fact that minorities have less, and worse, access to end-of-life care. And in a nation with an ageing population, 20% of whom identify as minorities, this is a problem. <http://www.theguardian.com/commentisfree/2015/nov/13/end-of-life-care-is-a-universal-right-that-functions-as-a-white-privilege>

End-of-life care on the Isle of Man

Review into end-of-life care due next year

U.K. (Isle of Man) | Energy FM (Douglas) – 11 November 2015 – Details of a review into end-of-life care on the Isle of Man will be published early next year. The Department of Health & Social Care has confirmed a report – carried out as part of a British audit process this summer – will be published in February. A number of audits have been undertaken over the last 18-months following the withdrawal of the Liverpool Care Pathway in August 2013. It’s to ensure standards of care have been maintained – the U.K. benchmarking report is due out in March. http://www.energyfm.net/cms/news_story_399001.html

Noted in Media Watch, 16 July 2012, #262 (p.4):

- U.K. (ISLE OF MAN) | Energy FM (Douglas) – 13 July 2012 – **‘New plans being introduced for “end of life care.”’** The Island’s first ever end-of-life care framework has been launched following months of detailed research and analysis.¹ http://www.energyfm.net/cms/news_story_223176.html

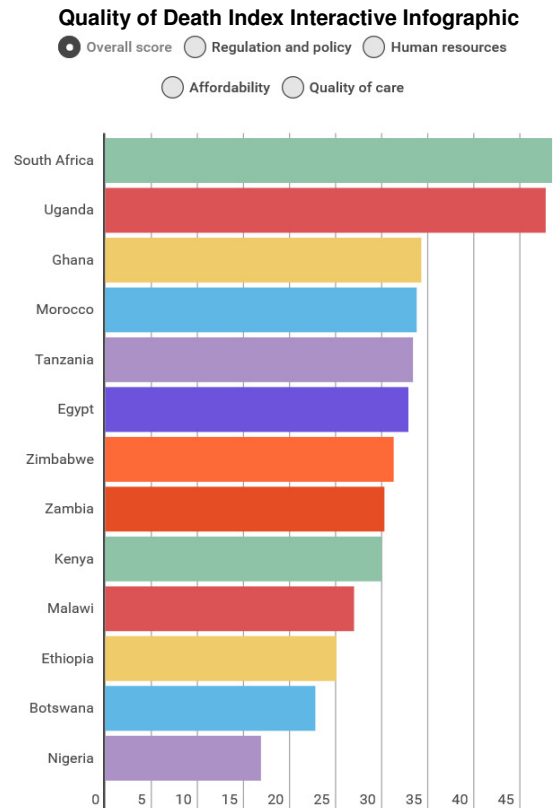
1. ‘End of Life Care Framework & Implementation Plan for Adults 2012-2015,’ Department of Health. <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/11673N6U/endoflifecareframeworkandimple.pdf>

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>

Morbid but fascinating: The Quality of Death Index, where South Africa and Uganda lead, and Nigeria trails

AFRICA | *The Mail & Guardian* (Nairobi, Kenya) – 9 November 2015 – The [Quality of] Index, compiled by the Economist Intelligence Unit (EIU),¹ highlights the advances that countries are making in taking care of their citizens at the end of life, as well as the remaining challenges and gaps in policy and infrastructure. It's morbid, but important stuff – although Africa is still overwhelmingly young, the proportion of older people in the population is rising, and non-communicable diseases such as heart disease, diabetes and cancer are on the rise. The need for long term, palliative care (PC) is also therefore set to rise significantly. The index ranks countries across five categories: the healthcare environment (government spending, regulation and policy), human resources, affordability of care, quality of care and the level of community engagement. Thirteen African countries were included in the index. South Africa tops the overall African rankings in the quality of end-of-life care, with a score of 48.5 out of a possible 100. Uganda comes in second, at 47.8 and Ghana is third, at 34.3. Although in the global rankings there is a strong correlation between income levels and success in delivering PC services, the link is weaker in the African context. Nigeria – Africa's biggest economy – comes in last (13th) in the quality of PC, with a score of just 16.9; Botswana, Africa's sixth-richest country by per capita gross domestic product, performs marginally better at 12th place (score 22.8), and Ethiopia, Africa's fastest growing economy is in position



11, with a score of 25.1. Countries with a high “quality of death” share several characteristics, the EIU highlights, including a strong and well-implemented national PC policy framework, high levels of public spending on health care services and medical workers who are well-trained on PC. They also have generous subsidies to relieve the financial burden of PC on patients, wide availability of opioid painkillers such as morphine, and strong public awareness on PC. Uganda is the star performer in the Index, considering its relatively small economy. Ranked second overall, Uganda beats all the other African countries in the training and skills of its medical workers to deliver end-of-life care; second in the quality of care received, and fourth in supportive policy and regulatory framework. <http://mgafrica.com/article/2015-11-06-quality-of-death-index>

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

End-of-life care in New Zealand

New panel to advise on palliative care services

NEW ZEALAND | Scoop.nz – 9 November 2015 – Health Minister Jonathan Coleman says a new expert panel will provide advice to the Ministry of Health on palliative care (PC) services for adults. “Palliative care is a priority for the Government and we are keen to ensure high quality and well-coordinated care is available to all who need it,” says Dr. Coleman. “That’s why the Government invested an extra \$76.1 million into hospice sustainability and PC services in aged residential care, primary care and community care. “The funding boost will help expand community PC services so they can better support terminally ill

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people at home and in aged-care facilities. It will also go towards the recruitment of up to 60 new nurse specialists, PC educators and other roles at hospices. We recognise the need for systematic clinician and consumer input to ensure the development of first-class PC. To help achieve this, the Ministry of Health is leading a major quality improvement work programme.” The new Palliative Care Advisory Panel will support the implementation of the PC work programme at a critical time, including the current Review of Adult Palliative Care Services and advise the Ministry on key issues such as equity of access and quality of care. The 11 member panel was selected following an Expressions of Interest process and has a wide range of sector expertise. Including representation from the aged care, consumer, district health boards, hospice, and research sectors. <http://www.scoop.co.nz/stories/PA1511/S00138/new-panel-to-advise-on-palliative-care-services.htm>

Noted in Media Watch, 31 August 2015, #425 (p.7):

- NEW ZEALAND | Radio New Zealand – 27 August 2015 – **‘Palliative care review announced.’** The review, to be conducted by the Ministry of Health and a palliative care advisory panel, will focus on improving services in the next three to five years, while considering the likely demand for those services in the next 10 to 20 years. It will cover primary and specialist services, and all care settings, including the home, hospitals, hospices and aged residential care facilities. The final report is expected by September 2016. <http://www.radionz.co.nz/news/bites/282544/palliative-care-review-announced>

Noted in Media Watch, 25 May 2015, #411 (p.5):

- NEW ZEALAND | Scoop (Wellington) – 21 May 2015 – **‘\$76.1 million more for palliative care and hospices.’** From 1 July 2015, \$13 million is being allocated each year to help hospices expand community palliative care (PC) services to better support terminally ill people at home and in aged-care facilities. An additional \$3.1 million in 2015/2016, rising to \$7 million from 2016/2017, will support the recruitment of nurse specialists, PC educators... <http://www.scoop.co.nz/stories/PA1505/S00328/761m-more-for-palliative-care-and-hospices.htm>

N.B. New Zealand was ranked 3rd of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit. http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Home care in England

The home carers who just couldn’t care less...investigation reveals a third of home-care providers fail to meet even basic standards

U.K. (England) | *The Daily Mail* – 9 November 2015 – Failing home-care providers have been warned by a Government Minister they must “shape up or shut down” after it was revealed nearly a third of agencies are failing to meet basic quality standards. Thousands of elderly and vulnerable patients are being “neglected” because of missed visits, given the wrong medication or left at risk of injury, indicating “a desperate, growing crisis in care.” In other cases, proper background checks on staff are not being carried out. A total of 424 out of 1,357 services across England have received “inadequate” or “needs improvement” ratings, according to figures ... from industry watchdog the Care Quality Commission. The shocking findings cover inspections carried out over the past year – October 2014 to October 2015 – of companies approved to provide the support workers who visit homes, allowing people to live independently. <http://www.dailymail.co.uk/health/article-3308539/Exposed-home-carers-just-couldn-t-care-investigation-reveals-home-care-providers-fail-meet-basic-standards.html>

Related:

- U.K. (England) | Online – *The Daily Telegraph* – 12 November 2015 – **‘Costly care homes may not be the best, league tables reveal.’** Analysis of official data shows that the areas with the most expensive residential care have some of the worst ratings from regulators. Meanwhile areas which provided some of the cheapest accommodation received far higher ratings from the inspectorate... <http://www.telegraph.co.uk/news/health/elder/11988560/Costly-care-homes-may-not-be-the-best-league-tables-reveal.html>

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

End-of-life care in Canada

The prevalence of medical error related to end-of-life communication in Canadian hospitals: Results of a multicentre observational study

BMJ QUALITY & SAFETY | Online – 9 November 2015 – In the hospital setting, inadequate engagement between healthcare professionals and seriously ill patients and their families regarding end-of-life decisions is common. This problem may lead to medical orders for life-sustaining treatments that are inconsistent with patient preferences. The prevalence of this patient safety problem has not been previously described. From 16 hospitals in Canada, 808 patients and 631 family members were included in this study. When comparing expressed preferences and documented orders for use of CPR, 37% of patients experienced a medical error. Very few patients (8, 2%) expressed a preference for CPR and had CPR withheld in their documented medical orders (undertreatment). Of patients who preferred not to have CPR, 174 (35%) had orders to receive it (overtreatment). There was considerable variability in overtreatment rates across sites (range: 14–82%). Patients who were frail were less likely to be overtreated; patients who did not have a participating family member were more likely to be overtreated. Medical errors related to the use of life-sustaining treatments are very common in internal medicine wards. Many patients are at risk of receiving inappropriate end-of-life care. <http://qualitysafety.bmj.com/content/early/2015/11/08/bmjqs-2015-004567.abstract>

Related:

- *PALLIATIVE MEDICINE* | Online – 4 November 2015 – ‘**Quantifying the burden of opioid medication errors in adult oncology and palliative care settings: A systematic review.**’ This review has highlighted the paucity of the literature examining opioid error incidence, types and patient impact in adult oncology and palliative care (PC) settings. Defining, identifying and quantifying error reporting practices for these populations should be an essential component of future oncology and PC quality and safety initiatives. <http://pmj.sagepub.com/content/early/2015/11/04/0269216315615002.abstract>

Noted in Media Watch, 10 February 2014, #344 (p.7):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 February 2014 – ‘‘**Please describe from your point of view a typical case of an error in palliative care**’’: **Qualitative data from an exploratory cross-sectional survey study among palliative care professionals.**’ Potential areas for errors were identified: 1) Drug treatment; 2) Palliative sedation; 3) Communication; 4) Care organization; 5) Treatment plan; 6) End-of-life care; and, 7) History taking. Six categories emerged as causes of errors: 1) Miscommunication; 2) System failure; 3) Dysfunctional attitudes; 4) Lack of knowledge; 5) Wrong use of technology; and, 6) Misjudgement. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0356>

Noted in Media Watch, 12 November 2012, #279 (p.8):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 November 2012 – ‘**Errors in palliative care: Kinds, causes, and consequences: A pilot survey of experiences and attitudes of palliative care professionals.**’ Professionals acknowledge errors – in particular errors in communication – to be a common and relevant problem in PC, one that has, however, been neglected in training and research. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0272>



An American perspective

A better death in Britain?

BROOKLYN JOURNAL OF INTERNATIONAL LAW, 2015;40(3):869-915. International comparisons of health outcomes indicate the U.S. ranks poorly among wealthy, developed countries on all measures of health, with the exception of self-reported subjective health status. In the U.S., overall health is poor compared with European countries, yet Americans believe they are in good shape. This striking evidence of self delusion is symptomatic of the larger problem we face with respect to life and death – the unwillingness to confront mortality. Patients and physicians often avoid discussing the inevitability of death and planning for it, and therefore miss opportunities to make choices comport with their values and preferences. In the absence of such decisions, the default model is to “err on the side of life,” which often results in overtreatment or inappropriate prolongation of life and avoidable suffering. Overtreatment at the end of life arises not just from the patient’s denial of mortality, but from a multiplicity of systemic influences such as lack of training in end-of-life care and the fear of accusations of hastening death. Patients may have difficulty acknowledging death is imminent, but worse, physician often do not inform their patients their prognosis is poor or even that they are dying. The medical system in the U.S. places much more emphasis on treatment and cure than on broader notions of patient care that include alleviation of physical and emotional suffering in the final stages of terminal illness. Many still view death as a failure of medicine rather than as a natural event that requires all of the physician’s skill to make it as peaceful and dignified as possible. <http://brooklynworks.brooklaw.edu/cgi/viewcontent.cgi?article=1109&context=bjil>

End-of-life care in Australia

The challenges of end-of-life care in acute hospitals

COLLEGIAN (The Australian Journal of Nursing Practice, Scholarship & Research), 2015;22(3):241-242. The Australian Commission on Safety & Quality in Health Care released a national Consensus Statement titled ‘Essential Elements for Safe & High-Quality End-of-Life Care.’¹ This document, targeted at acute health services including intensive care, was written following consultation with health consumers, carers and experts in the field. The purpose was to describe the elements essential for delivering safe and high quality end of life care in Australia... The Consensus Statement makes recommendations about practice in acute care settings where end-of-life care is provided. This publication is a positive and essential move forward but for the nursing workforce in particular, several significant problems remain, and lack due attention in the Consensus Report. [http://www.collegianjournal.com/article/S1322-7696\(15\)00055-4/fulltext](http://www.collegianjournal.com/article/S1322-7696(15)00055-4/fulltext)

1. ‘Essential Elements for Safe & High-Quality End-of-Life Care,’ Australian Commission on Safety & Quality in Health Care, June 2015. [Noted in Media Watch, 1 June 2015, #412 (p.6)] <http://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-for-safe-high-quality-end-of-life-care.pdf>

Related:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 November 2015 – ‘**Impact of staffing on access to palliative care in U.S. hospitals.**’ The objective of this report is to examine the impact of palliative care (PC) program staffing on access to PC in U.S. hospitals. Hospital-based PC programs reported an average service penetration of 4.4%. Higher staffing levels were associated with higher service penetration; higher service penetration was associated with shorter time to initial PC consultation. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0436>

Noted in Media Watch, 7 September 2015, #426 (p.16):

- *PALLIATIVE MEDICINE* | Online – 1 September 2015 – ‘**Palliative care in hospital: Why is it so difficult?**’ Care of the dying used to be the bread and butter of family doctors – why and where has that confidence gone? At the same time, families are not available or confident to care, community services are fragmented, we do not talk about dying, and we do not prepare or plan ahead. The end result ... is that thousands of people are admitted to hospital every day, and culture and systems make it very difficult to escape. <http://pmj.sagepub.com/content/early/2015/08/28/0269216315600996.full>

The validity of advance directives in acute situations: A survey of doctors' and relatives, perceptions from an intensive care unit

DEUTSCHES ÄRZTEBLATT INTERNATIONAL, 2015;112(43):723-729. Nearly every fourth person in Germany has an advance directive (AD) that is to be used in certain medical situations. It is questionable, however, whether ADs truly influence important treatment decisions in the intensive care unit (ICU). A study was carried out among the physicians and relatives of 50 patients with ADs who were hospitalized on four different multidisciplinary ICUs. In most of the ADs, the conditions under which they were meant to apply were stated in broad, general terms... In assessing whether the AD was applicable to the situation at hand, the strength of agreement between physicians and relatives as well as between the two groups of physicians was only fair and non-significant... The relatives found the ADs more useful than the doctors did ... and favored their literal application... These groups' clearly differing assessments of the applicability of ADs imply that the currently most common types of advance AD are not suitable for use in intensive care. <https://www.aerzteblatt.de/int/archive/article?id=172639>

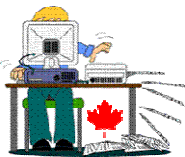
Related:

- *INDIAN JOURNAL OF CRITICAL CARE MEDICINE*, 2015;19(11):655-660. '**Framework for decision-making and management of end-of-life decisions in Intensive Care Units: A modified protocol.**' End-of-life decisions are being made daily in ICUs... The spectrum of options varies from full-continued care, withholding treatment, withdrawing treatment, and active life-ending procedures depending on the institutional practices and legal framework. Considering the complexity of the situation and the legalities involved, it is important to have a structured approach toward these sensitive decisions. <http://ijccm.org/article.asp?issn=0972-5229;year=2015;volume=19;issue=11;spage=655;epage=660;aulast=Kumar>

Applying palliative care principles and practice to emergency medicine

EMERGENCY MEDICINE AUSTRALASIA | Online – 11 November 2015 – Only recently has the potential (unmet) palliative care (PC) workload in the emergency department been recognised. While confident in PC symptom management, we underestimate the role of a palliative approach in non-cancer diagnoses and seek education in areas such as individual patient care pathways, ethical and legal issues, and difficult conversations at the end of life. PC is best introduced early for a range of life-limiting cancer and non-cancer diagnoses. Allowing patients time to tell their story with active listening, acknowledgement of suffering and a compassionate presence leads to treatment "success" that is not defined by cure. This patient-centred, rather than disease-centred approach, is the essence of PC, and one that is easily incorporated into emergency practice. PC and disease-specific treatments can comfortably coexist, and with meticulous symptom management, may actually prolong life. <http://onlinelibrary.wiley.com/doi/10.1111/1742-6723.12494/abstract>

N.B. Selected articles on palliative care patients who present to the emergency department noted in past issues of Media Watch are listed in the issue of the weekly report of 7 September 2015, #426 (pp.13-14).



[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>

**Caring for dying cancer patients in the Chinese cultural context:
A qualitative study from the perspectives of physicians and nurses**

EUROPEAN JOURNAL OF ONCOLOGY NURSING | Online – 4 November 2015 – Disclosure of information on death and cancer to dying cancer patients is taboo in traditional Chinese culture, which greatly decreases the physicians' and nurses' effective communication with dying patients in end-of-life (EOL) care. Both described strong ambitions to give dying cancer patients high-quality care, and they emphasized the importance of maintaining dying patients' hopes in the death-denying cultural context. However, the nurses were more concerned with dying patients' physical comfort and wish fulfillment, while the physicians placed greatest emphasis on patients' rights and symptom management. Both suffered whilst also benefitting from taking care of dying patients, which helped with their personal growth and allowed greater insight into themselves and their clinical practice. Results of this study indicated that Chinese physicians and nurses require improved methods of communication on EOL care, as well as needing more support to provide quality EOL care. [http://www.ejoncologynursing.com/article/S1462-3889\(15\)30034-X/abstract](http://www.ejoncologynursing.com/article/S1462-3889(15)30034-X/abstract)

“Our only child has died” – A study of bereaved older Chinese parents

OMEGA – JOURNAL OF DEATH & DYING | Online – Accessed 10 November 2015 – In China, the unintentional consequence of the one child policy has emerged. There, the group of older adults who lost their only child is called shiduers. This study compared 42 older adults who lost their only child to 33 older adults who have a child, in term of their physical and mental health, and social support. The results confirmed the general deteriorating trend in those aspects of the bereaved Chinese parents' life after their only child's death. The results also revealed the impairments on the shiduers' physical, mental, and social aspects were significant, comparing to the clinical diagnosis cut off points used in Western countries. http://www.researchgate.net/profile/Yongqiang_Zheng/publication/283317063_Our_Only_Child_Has_DiedA_Study_of_Bereaved_Older_Chinese_Parents/links/56327e4b08ae242468d9f908.pdf

Noted in Media Watch, 8 September 2014, #374 (p.5):

- *PROGRESS IN PALLIATIVE CARE* | Online – 4 September 2014 – ‘**The complexities of communicating palliative care in Chinese-based languages.**’ This opinion paper raises the many complexities in endeavouring to understand how palliative care is portrayed in Chinese-based cultures which have many distinctive traditions associated with the end of life, including limitations around the use of language. <http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.0000000106>

Noted in Media Watch, 21 July 2014, #367 (p.10):

- *JOURNAL OF GERIATRICS & PALLIATIVE CARE*, 2014;2(2). ‘**Australian Chinese patient’s experiences of palliative care services.**’ This study shows Australian Chinese understand the role of palliative care. Changes in perception in areas such as disclosure of the truth of a disease and openness in discussing issues related to death and dying are highlighted. Traditional Chinese values still play a role in shaping their attitudes regarding decision-making, and hydration and nutrition during end-of-life care. <http://www.avensonline.org/wp-content/uploads/2014/06/JGPC-2373-1133-02-0004.pdf>

Related:

- *ACTA BIOETHICA*, 2015;21(2):173-182. ‘**End-of-life decisions: A survey of the perspectives of people in Korea, China, and Japan.**’ Three East Asian countries, Korea, China, and Japan, have shared a similar cultural background throughout history. This is the basis of the assumption of Asian values in the field of bioethics. However, different processes of modernization and healthcare systems have resulted in considerable differences. Along with the aging process, end-of-life care issues have been increasing in importance in these three countries. The authors conducted a study of 899 lay persons in 3 countries regarding their perspectives about end-of-life decisions: 1) Favorable ways of decision-making in end-of-life care; 2) Institutional and legal devices; 3) Withdrawal of life-sustaining treatment; and, 4) Euthanasia. <http://revistaderechopublico.uchile.cl/index.php/AB/article/viewArticle/37549>

N.B. English language article. Click on ‘Texto completo: [PDF](#)’ to access full text.

Bereavement support in intensive care: Practical considerations

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;22(6):275-277. Bereavement follow-up in the ICU is widely seen as best practice. It forms a key component of the U.K. Intensive Care Society guidelines and is promoted extensively in the literature. However, there are many uncertainties and little guidance on the format and objectives of bereavement follow-up meetings. The authors highlight the importance of recognising complicated grief while showing how difficult it can be to distinguish it from normal grief. They explain that the tools currently available to screen people for complicated grief are not clinically practical, highlight some suggestions, and stress that any bereavement follow-up meeting should be underpinned by a thorough psychosocial assessment. The authors illustrate the need for training and for a multidisciplinary approach in this highly specialist area. The literature

shows that ICU-based bereavement follow-up programmes are hugely desirable and popular. In spite of this, we should stop and consider. What is the value of such programmes? How should they be carried out, for whom and by whom? Are they effective in terms of outcomes and in terms of cost? Clinically validated research is urgently needed to improve bereavement follow-up in the ICU.



Cont. next page

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.

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Something Missed or Overlooked?

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

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 November 2015 – **‘Building community capacity in bereavement support: Lessons learnt from bereaved caregivers.’** Most bereaved people do not require specialist intervention, yet building community capacity in providing bereavement support is underdeveloped. While family caregivers indicate a need for more information about bereavement, there is little evidence to guide what this information might contain. <http://ajh.sagepub.com/content/early/2015/11/12/1049909115615568.abstract>
- *ARTIFICIAL ORGANS* | Online – 3 November 2015 – **‘When left ventricular assist devices patients die: The caregiver’s mourning.’** Positive aspects reported by caregivers [i.e., study participants] were the patient’s subjective well-being and increased survival. Negative aspects included the incomplete autonomy of the patient. Half of caregivers reported not being advised about many of the problems they would face. Early intervention of palliative care could prevent or reduce complicated mourning. <http://onlinelibrary.wiley.com/doi/10.1111/aor.12594/abstract?userIsAuthenticated=false&deniedAccessCustomisedMessage>
- *COMMUNICATIONS*, 2015;40(4):403-423. **“‘Help me. I am so alone.’ Online emotional self-disclosure in shared coping-processes of children and adolescents on social networking platforms.’** The substantial usage of social network platforms can be considered an extension of children’s and adolescents’ personal social environment. Furthermore, topics on bereavement platforms ultimately go beyond grief, as children and adolescents also include emotions such as hope, gratitude and cohesiveness. Communication within online bereavement communities thus enables a process known from offline communication as transformation from a loss-oriented to restoration-oriented coping... <http://www.degruyter.com/view/j/comm.2015.40.issue-4/comm-2015-0018/commun-2015-0018.xml>

Integrating hospice and palliative care in Austrian nursing homes

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;22(6):282-284. In 2006, Hospice Austria – the umbrella organisation for hospice and palliative care (PC) in Austria – started working on a project aimed at integrating hospice and PC in nursing homes in order to improve the quality of life of residents and carers. The project consists of a two-year organisational development process combined with staff training in palliative geriatrics. Nursing homes are expected to train 80% of all their staff. In May 2015, out of around 800 nursing homes in Austria, 100 had implemented the project or were in the process of doing so. Hospice Austria is now working on improving advance care planning in nursing homes, and has also set itself a new challenge: introducing hospice and PC in organisations that provide basic home care.

Quotable Quotes

No one’s death comes to pass without making some impression, and those close to the deceased inherit part of the liberated soul and become richer in their humanness. **Hermann Broch (Austrian Modernist, 1886-1951)**

N.B. Austria was ranked 17th of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, July 2015. [Noted in Media Watch, 19 July 2010, #158 (p.3)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Related:

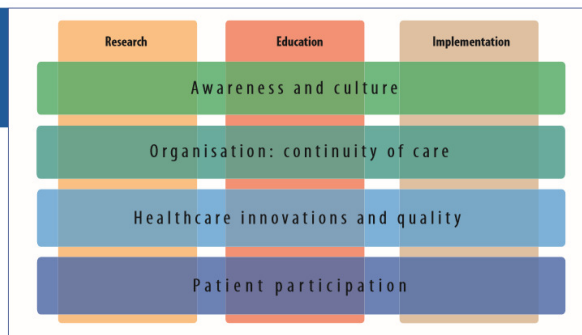
- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(6):296-298. **‘Providing palliative care education to staff in elderly care settings in New Zealand.’** In New Zealand, an increasing proportion of people will spend their last months or years of life in residential care for the elderly. The Fundamentals of Palliative Care training programme is designed to teach palliative care knowledge, skills and attitudes to staff working in New Zealand’s elderly care facilities. The training programme comprises nine learning packages. In 2012, it was delivered to 7,136 participants. Following the success of Fundamentals of Palliative Care, a generic resource is being developed that will be usable in any setting.

What you need to know about alcohol in palliative care: A brief review of the literature

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;22(6):292-295. Overall, it seems that, in the palliative care (PC) setting, the main concern is to identify whether or not a patient has alcohol dependence. Detoxification may not be needed, but identification is crucial so that any symptoms potentially exacerbated by alcohol dependence can be appropriately managed. It is also important to identify alcohol dependence in order to manage any psychological problems that the patient may be self-managing with alcohol. Patients in PC who may have had the problem for a long time may not be aware that support is available. High-quality patient care should incorporate all aspects of patients' well-being and environment. However, it is also important to respect the patient's autonomy. If a patient does not want to address their alcohol addiction, this needs to be respected. More research is needed into the effects of unknown alcohol dependence in PC. Larger studies into how best to manage alcohol dependence are also needed, as much of the available evidence comes from case reports. A more current review of alcohol in PC needs to be conducted. Finally, research is needed into whether current alcohol screening tools are sufficient in identifying misuse in elderly patients or whether they need to be adapted.

Agora: Building bridges in palliative care in The Netherlands

Figure 1. The Dutch national programme of palliative care is built around the idea of a coherence between research, education and implementation



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2015;22(6):309-311. Many countries have opted for palliative care (PC) as a specialist field. This is not the case in The Netherlands. Here, the basic principle is that PC is part of regular, mainstream care. General healthcare providers like family doctors and nurses, and institutions such as hospices, nursing homes and hospitals, are all expected to be able to provide good PC. They are supported in that task by specialist multidisciplinary teams. General healthcare providers and PC facilities work together in networks to organise

care as efficiently as possible for those in the palliative phase. The Dutch government has a policy of transferring a number of responsibilities in the healthcare area to municipalities. The idea is that care is organised as close as possible to the patient's home. There is also a trend in society towards more control and responsibility resting with citizens. In the field of PC this can be difficult given the vulnerability and frailty of some patients. When the burden of care becomes too heavy, there can also be issues of stress for informal carers who support patients at home. How close to home should care be regulated? How is it possible to ensure that patients die in their preferred place? The Ministry of Health has advised that PC should be consistent with the policy of allowing people to remain at home for as long as possible, that volunteers and carers should be supported, and that municipalities and health insurers have a greater responsibility for care and support in the last phase of life.

Noted in Media Watch, 9 February 2015, #396 (p.9):

- *JOURNAL OF MEDICAL ETHICS* | Online – 3 February 2015 – ‘**Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience.**’ The hypothesis that legal regulation of physician-assisted dying slows development of palliative care is not supported. <http://jme.bmj.com/content/early/2015/02/03/medethics-2014-102116.abstract>

Noted in Media Watch, 31 October 2011, #225 (p.11):

- *BRITISH MEDICAL JOURNAL* | Online report – 24 October 2011 – ‘**Legalisation of assisted dying does not harm palliative care, study concludes.**’ The legalisation of assisted dying does not undermine the provision of good palliative care, a report comparing six European countries concludes.¹ <http://www.bmj.com/content/343/bmj.d6779.extract>

1. ‘Palliative Care Development in Countries with a Euthanasia Law.’ Report by the European Association of Palliative Care for the Commission on Assisted Dying Briefing Papers, October 2011. <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/NetCache/IE/87XQHXCX/PalliativeCareDev/nCWAEEuthanasiaLaw.pdf>

Tasking the tailor to cut the coat: How to optimize individualized ICU-based palliative care?

INTENSIVE CARE MEDICINE | Online – 10 November 2015 – Conducted in diverse patient populations, including those with advanced cancer, lung disease, and neurologic disease ... multiple studies evidence benefits associated with proactive palliative care (PC): improved quality of life, better symptom management, and higher family satisfaction. For these reasons, PC is being integrated throughout the continuum of medical care, including in intensive care units (ICUs). There are multiple conceptual models for whether PC is “integrative” and delivered by the ICU team, “consultative” and delivered by a specialist PC team, or “mixed” and delivered by a combination of the two. Studies suggest both consultative and integrative models of ICU-based care can be effective, and the “ideal” model for any ICU will likely vary by hospital and ICU resources, patient populations, and local culture. A variety of ICU-based PC delivery models have been evaluated, and yet more data on the effectiveness of different models are needed for individual ICUs to feasibly choose the delivery modality that is “right” for their unique circumstances. <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/UPG4XG0C/art%253A10.1007%252Fs00134-015-4107-4.pdf>

Noted in Media Watch, 6 July 2015, #417 (pp.10):

- *CLINICS IN CHEST MEDICINE* | Online – 27 June 2015 – ‘**Integration of palliative care services in the intensive care unit: A road map for overcoming barriers.**’ Current evidence promotes the integration of palliative care (PC) services within the intensive care unit (ICU) setting. PC bridges the gap between comfort and cure, and these services are growing in the U.S. This article discusses the benefits and barriers to integration of ICU and PC services, and a stepwise approach to implementation of PC services. [http://www.chestmed.theclinics.com/article/S0272-5231\(15\)00071-4/abstract](http://www.chestmed.theclinics.com/article/S0272-5231(15)00071-4/abstract)

N.B. Noted in this issue of Media Watch are additional articles on the Integration of PC in ICU.

Related:

- *ANNALS OF THE AMERICAN THORACIC SOCIETY*, 2015;12(11):1697-1699. ‘**Responding to requests for potentially inappropriate treatments in intensive care units.**’ Summary of the policy statement by the American Thoracic Society, American Association for Critical Care Nurses, American College of Chest Physicians, European Society for Intensive Care Medicine, Society of Critical Care. <http://www.atsjournals.org/doi/abs/10.1513/AnnalsATS.201508-565CME?journalCode=annalsats#.VkIF1DZdHyQ>

Perinatal palliative care

From pregnancy to palliative care: Advancing professional midwifery practice?

THE PRACTICING MIDWIFE, 2015;18(10):18-23. Historically midwives may have not considered palliative care (PC) as a part of their professional role. Enhanced technologies and antenatal screening have broadened the boundaries of care. However do midwives truly embrace the philosophy of PC into their practice? This paper presents the discussion around a case study that demonstrates the evolving area of advanced practice: perinatal PC. Midwives in fact have an important collaborative role to play in ensuring that PC for the baby and family starts as soon as a life-limiting condition is recognised, thus ensuring best care and support are provided for those parents and families for whom pregnancy sadly leads to PC. <http://www.ingentaconnect.com/content/mesl/tpm/2015/00000018/00000010/art00005>

Noted in Media Watch, 21 November 2011, #228 (p.4):

- U.S. (Illinois) | *The Chicago Tribune* – 21 November 2011 – ‘**Midwife also assists at the end of life.**’ While Ana Blechschmidt is a certified birth doula she also specializes in end of life. That makes her a death doula or death midwife. http://www.chicagotribune.com/news/columnists/ct-met-trice-death-doula-1114-20111121_0,6947868.column

N.B. Additional articles on perinatal PC are noted in the issue of Media Watch of 26 October 2015, #433 (p.14).

Locating care at the end of life: Burden, vulnerability, and the practical accomplishment of dying

SOCIOLOGY OF HEALTH & ILLNESS | Online – 7 November 2015 – Home is frequently idealised as the preferred location for end-of-life care, while in-patient hospital care is viewed with suspicion and fear. Yet, many people with a terminal illness spend their final days in some form of medicalised institutional setting, such as a specialist palliative care in-patient unit. The authors found [study] participants came to conceptualise home though a sense of bodily vulnerabilities and that they frequently understood institutional care to be more about protecting their family from the social, emotional and relational burdens of dying. For a significant number the experience of dying came to be understood through what could be practically accomplished in different locales. The different locales were therefore framed around providing the best care for the patient and their family. <http://onlinelibrary.wiley.com/doi/10.1111/1467-9566.12375/abstract>

Related:

- *PLOS ONE* | Online – 10 November 2015 – ‘**Do patients want to die at home? A systematic review of the U.K. literature, focused on missing preferences for place of death.**’ It is unknown what proportion of U.K. patients prefers to die at home. The authors found no clear difference between preferences for home and the diagnosis of patients. Ultimately, preferences for place of death appear to depend on who is asked the question; what, where, why and when they are asked, and how those without an answer are included. <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0142723>

Noted in Media Watch, 12 October 2015, #431 (p.9):

- *BRITISH MEDICAL JOURNAL* | Online – 7 October 2015 – ‘**Is home always the best and preferred place of death?**’ Death at home is not necessarily good. Just because a patient did not die at home does not necessarily mean their death occurred in the wrong place. It is important to recognise and accommodate the diversity of patient preferences for place of death, especially in the context of a cultural heterogeneity that is rarely researched or recognised. <http://www.bmj.com/content/351/bmj.h4855>
- *BMC MEDICINE* | Online – 9 October 2015 – ‘**Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study.**’ Where people died was, for most (80%), the place where they lived during their last week of life. Four factors explained 91% of home deaths: 1) Patient’s preference; 2) Relative’s preference; 3) Home palliative care; 4) Or district/community nursing. <http://www.biomedcentral.com/1741-7015/13/235/abstract>

The challenges of final conversations: Dialectical tensions during end-of-life family communication

SOUTHERN COMMUNICATION JOURNAL, 2015; This study examines how participants recall the challenges they encountered during final conversations they had with a family member who has since died. We use relational dialectics as a theoretical framework to interpret participants’ responses. The dialectical tensions evident in these conversations are influenced primarily by a chronemic pressure: the impending death. The overarching tensions discovered were acceptance – denial and openness –closedness (including expression of emotion – concealment of emotion). Practical and theoretical implications are discussed. <http://www.tandfonline.com/doi/abs/10.1080/1041794X.2015.1081975>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BMC PALLIATIVE CARE* | Online – 5 November 2015 – ‘**Determinants of favourable opinions about euthanasia in a sample of French physicians.**’ There is still no study in France on the development of opinion about euthanasia and its impact. The issue goes beyond the strictly professional sphere and involves broader socio-political stakes. These stakes do not necessarily take into account medical practices and experiences or the desires of end-of-life patients. The professional upheaval that the future French legal framework will doubtlessly trigger will require further research. <http://link.springer.com/article/10.1186/s12904-015-0055-6>

Worth Repeating

Mapping levels of palliative care development: A global update

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 26 September 2012 – The authors purpose was to categorize palliative care (PC) development, country by country, throughout the world, showing changes over time. Development is categorized using a six-part typology: Group 1 (no known hospice-PC activity) and Group 2 (capacity-building activity) are the same as developed during a previous study (2006), but Groups 3 and 4 have been sub-divided to produce two additional levels of categorization: 3a) Isolated PC provision, 3b) Generalized PC provision, 4a) Countries where hospice-PC services are at a stage of preliminary integration into mainstream service provision, and 4b) Countries where hospice-PC services are at a stage of advanced integration into mainstream service provision. In 2011, 136 of the world's 234 countries (58%) had at least one PC service – an increase of 21 (+9%) from 2006, with the most significant gains having been made in Africa. Advanced integration of PC has been achieved in only 20 countries (8.5%). Although more than half of the world's countries have a PC service, many countries still have no provision, and major increases are needed before PC is generally accessible worldwide. [Noted in Media Watch, 1 October 2012, #273 (p.11)] [http://www.jpsmjournal.com/article/S0885-3924\(12\)00334-X/abstract](http://www.jpsmjournal.com/article/S0885-3924(12)00334-X/abstract)

The 2015 Quality of Death Index Ranking palliative care across the world	The Economist	Intelligence Unit
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Figure 4.2: Availability of public funding for palliative care

5		4		3		2		1	
There are extensive government subsidies or programmes for individuals accessing palliative care services. The qualification criteria are clear and the process to access such funding is largely easy and smooth. Information on how to access such funding is widely available. The effectiveness of programmes is routinely and adequately monitored.		There are adequate government subsidies for individuals accessing palliative care services. The qualification criteria are clear and the process to access such programmes is largely easy and smooth. The effectiveness of programmes is unevenly monitored.		There are adequate government subsidies or programmes for individuals accessing palliative care services. The qualification criteria are clear, but funds and programmes are difficult to access. The effectiveness of programmes is not monitored.		There is a limited number of government subsidies or programmes for individuals accessing palliative care services. Where available, the qualification criteria are unclear, and funds and programmes are difficult to access.		There are no government subsidies for individuals accessing palliative care services.	
Australia	Ireland	Canada	New Zealand	Austria	Malaysia	Argentina	Myanmar	Bangladesh	Malawi
Belgium	Japan	Chile	Norway	Colombia	Mexico	Botswana	Philippines	Dominican	Nigeria
Denmark	UK	Cuba	Panama	Costa Rica	Mongolia	Brazil	Poland	Republic	Puerto Rico
		Finland	Singapore	Czech	Peru	Bulgaria	Romania	Egypt	Tanzania
		France	South Korea	Republic	Portugal	China	Slovakia	Iraq	
		Germany	Sweden	Ecuador	Russia	Ethiopia	South Africa		
		Hong Kong	Switzerland	Ghana	Saudi Arabia	Guatemala	Sri Lanka		
		Italy	Taiwan	Greece	Spain	India	Thailand		
		Netherlands	US	Hungary	Uganda	Indonesia	Turkey		
				Jordan	Uruguay	Iran	Ukraine		
				Kazakhstan	Venezuela	Israel	Zambia		
				Kenya	Vietnam	Morocco	Zimbabwe		
				Lithuania					

'2015 Quality of Death Index' (see p.37): http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Media Watch: Online

International

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