

## Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

For selected “coverage” of the Economist Intelligence Unit report scroll down to **Canada** (below), **U.S.** (p.3), **International** (p.6) and **Specialist Publications** (p.15). Scroll down to p.19 for ‘Quality of Death Index – Overall Scores’ of the 80 countries surveyed.



The 2015 Quality of Death Index  
Ranking palliative care across the world

## Canada

### 2015 Quality of Death Index

#### Canada edged out of Top 10 in quality of death report

*THE TORONTO STAR* | Online – 8 October 2015 – Where on earth is the best place to die? This week, the Economist Intelligence Unit (EIU) tried to answer that question with its second Quality of Death report, which ranked 80 countries on palliative care and end-of-life support.<sup>1</sup> Here’s a look at the best, the worst, and why Canada couldn’t crack the Top 10. Canada was edged out of the Top 10 this year, ranking 11th. (The first Quality of Death report,<sup>2</sup> published in 2010, had Canada tied for 9th with the U.S., but because it used a different methodology it can’t be directly compared with this latest one [see p.11 of the EIU report]). While Canada remains a top global performer, the rankings suggest one’s dying days are better spent in New Zealand or Taiwan. Two weaknesses pushed Canada down the list, according to Sharon Baxter, executive director with the Canadian Hospice Palliative Care Association. One is that Canada still lacks a strong national strategy. The other, surprisingly, is in the category of affordability, where Canada ranked 22nd. “Even though Canada professes to be a publicly-funded system, a lot of the care in the last year or two of life is provided while you’re still at home,” Baxter said. “Our health care system, besides hospital care, doesn’t really cover a lot of that. So what you (see) coming out of the pockets of Canadians is actually increasing.” <http://www.thestar.com/news/world/2015/10/08/canada-edged-out-of-top-10-in-quality-of-death-report.html>

1. ‘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](http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf)
2. ‘2010 The Quality of Death: Ranking End-of-Life Care Across the World,’ Economist Intelligence Unit. [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

**N.B.** Scroll down to p.19 of this issue of Media Watch for ‘Quality of Death Index – Overall Scores’ of the 80 countries surveyed.

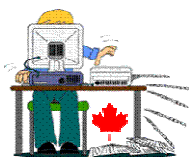
## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online – 8 October 2015 – ‘**Doctor-assisted suicide rules may fall to province, ethics expert says.**’ There are far more questions than answers about doctor-assisted suicide and how it will work in Canada once new legislation takes effect early next year, says a University of Manitoba ethics expert who's part of a panel advising provinces and territories. The questions that need to be answered before the 6 February deadline include how it will be administered, who will be eligible and what happens when doctors say no, said bioethicist Arthur Schafer, a member of the provincial-territorial expert advisory group on physician-assisted dying. If the federal government comes up with new legislation to deal with those questions, it will have to conform to the Supreme Court ruling, Schafer said. If it doesn't, the onus will fall on another level of government. <http://www.cbc.ca/news/canada/manitoba/doctor-assisted-suicide-rules-may-fall-to-province-ethics-expert-says-1.3262463>

Noted in Media Watch, 17 August 2015, #423 (p.3):

- ONTARIO | CBC News – 14 August 2015 – ‘**Ontario forms expert panel on assisted dying.**’ The Ontario government is setting up an advisory group to study physician-assisted dying, leading 11 provinces and territories in examining the controversial subject. The panel is similar to the one established by the federal government to inform its end-of-life legislation. The federal, provincial and territorial governments will need to craft laws around the court ruling by February 2016, when the ruling takes effect. Ontario and the participating provinces and territories say the primary responsibility to provide health care resides with them, and the panel will craft their response to the court ruling. <http://www.cbc.ca/news/canada/toronto/ontario-forms-expert-panel-on-assisted-dying-1.3191186>
- MANITOBA | BBC News – 7 October 2015 – ‘**Manitoba College of Physicians & Surgeons seeks input on doctor-assisted suicide.**’ Registrar Dr. Anna Ziomek says a working group was set up in the spring. It has 12 members including doctors, members of the public, a student, administrators, a palliative care physician and a representative of Dying with Dignity, an advocacy organization lobbying to give Canadians end-of-life choices. The Manitoba college is trying to determine what role, if any, a doctor will play, or if he or she refuses to participate, what at a minimum should be expected of them. <http://www.cbc.ca/news/canada/manitoba/manitoba-college-of-physicians-and-surgeons-seeks-input-on-doctor-assisted-suicide-1.3260994>
- QUEBEC | *The National Post* – 6 October 2015 – ‘**Quebec medical system tries to put a price on death ahead of enacting right-to-die law.**’ Quebec and its doctors are grappling with one of the most delicate discussions in the realm of assisted dying... They are expected to begin discussing fees for “medical aid in dying” as the province prepares to enact its historic right-to-die legislation in December. A health ministry spokeswoman said doctors would be remunerated for euthanasia “proceedings” under existing billing agreements. While no separate fee code has been negotiated, “Discussions are to be expected with the medical federations to assess the appropriateness of adapting existing codes.” Any fee schedule could become a model for all of Canada in February, when assisted dying is set to become legal across the nation. <http://news.nationalpost.com/news/canada/1007-na-price>



### 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>

## U.S.A.

### 2015 Quality of Death Index

#### The world's best and worst places to die...

*THE WASHINGTON POST* | Online – 7 October 2015 – No one likes to think about the end, even if everyone knows it's coming. We prefer to prepare for more joyful milestones: birthdays and marriages, graduations and employment. These all factor into our measures of well-being – our quality of life. We're repeatedly told to plan for retirement, yet we rarely talk about what will happen at the end of that slow sunset. As a result, according to the Economist Intelligence Unit [EIU], we neglect to think about "dying better." In its second 'Quality of Death Index' ... the Economist ranks the quality of palliative care in 80 countries.<sup>1</sup> As it did in 2010, the U.K. comes out on top. The U.S. ranks ninth. The report distinguishes between end-of-life care and palliative care, which is defined by the World Health Organization as limited not only to care in the final stages of a terminal illness, but also includes early assessments, psychological attention and support systems. Though America's score of 80.8 (out of 100) is respectable, it's far below the 93.9 garnered by its mates across the pond. <http://www.washingtonpost.com/news/morning-mix/wp/2015/10/07/its-better-to-die-in-the-uk-than-in-america-according-to-a-new-quality-of-death-index/>

1. '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](http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf)

**N.B.** The study was commissioned by the philanthropic organization The Lien Foundation, of Singapore. Scroll down to p.19 of this issue of Media Watch for 'Quality of Death Index – Overall Scores' of the 80 countries surveyed. The Economist Intelligence Unit's 2010 quality of death index, also commissioned by the Lien Foundation, was noted in the issue of Media Watch of 19 July 2010, #158 (p.3), and can be downloaded at: [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

Related:

- CALIFORNIA | *The Sacramento Bee* – 7 October 2015 – '**What about the rest of us at life's end?**' Now that the debate about physician aid in dying [in California] has mercifully ended, is there any oxygen left in the room? A troubling aspect of the end-of-life debate was that it was dominated by an approach that only a handful of Californians will seek out. We need to focus on the harder work of change so the rest of us can live better when we don't actually want to die. In the four other states that approved aid in dying, only a few hundred have actually sought the assistance. California's 200,000-plus annual deaths might yield a few hundred to a 1,000 cases a year. Many more inquire about than undertake aid in dying because most of us want a better end and often the request is a cry for help. Those requests reflect profound suffering associated with physical pain, as well as loneliness and spiritual crisis, capped by a loss of control. These common, excruciating handmaidens on the journey of death afflict patients with a range of conditions, affecting more than two-thirds of Americans in the final year of their lives in 2010. <http://www.sacbee.com/opinion/op-ed/soapbox/article38106846.html>

#### U..S. Rankings

	Rank/80	Score/100
Quality of Death overall score (supply)	9	80.8
Palliative and healthcare environment	6	78.9
Human resources	14	70.2
Affordability of care	=18	82.5
Quality of care	=8	90.0
Community engagement	=9	75.0

#### Extract from *The Washington Post* report

The Economist Intelligence Unit credits the Affordable Care Act [see p.38 of the EIU report] with helping deliver sweeping changes throughout the U.S. health-care system, though the private sector has also developed ways of delivering on the increased demand for palliative services.

#### Specialist Publications

'The impact of race on intensity of care provided to older adults in the medical intensive care unit' (p.15), in *Journal of Racial & Ethnic Health Disparities*.

## Discussing life expectancy gives advanced cancer patients realistic view

REUTERS | Online – 7 October 2015 – When doctors discuss prognosis with advanced cancer patients, those patients have more realistic views of their life expectancy and don't seem to experience a decrease in emotional wellbeing, according to a new study.<sup>1</sup> "That the vast majority of cancer patients who are dying say that they want to know their prognosis seems surprisingly courageous," said senior author Holly G. Prigerson of Weill Cornell Medical College... Every patient needs to know that their prognosis, including life expectancy, and expected outcomes of treatment, for example they should know that chemotherapy cannot cure incurable cancer, Prigerson said. "Providers often are reluctant to communicate grim news, as anyone would be," she said. The study included 590 patients with advanced, metastatic cancer who had been treated with at least one round of palliative che-

motherapy, which is meant to improve comfort rather than to cure. Researchers asked patients whether their oncologist had ever given them a prognosis with a life expectancy estimate, then asked the patients to estimate their own life expectancy and to complete assessments of emotional distress, whether they had advance directives and their end-of-life care preferences. <http://www.reuters.com/article/2015/10/07/us-health-cancer-prognosis-idUSKCN0S12DB20151007>

### **Specialist Publications**

'New guidelines for primary palliative care in oncology' (p.16), in *Medscape*.

1. 'Outcomes of prognostic disclosure: Associations with prognostic understanding, distress, and relationship with physician among patients with advanced cancer,' *Journal of Clinical Oncology*, 5 October 2015. <http://jco.ascopubs.org/content/early/2015/09/29/JCO.2015.61.9239.abstract>

## Inmates help other prisoners face death in hospice program

OHIO | Associated Press – 6 October 2015 – As late-morning sun streams through narrow prison windows, convicted killer Scott Abram stands beside a fellow inmate, speaks quietly to him... The prisoner appears to smile, but it's difficult to gauge his response. He is dying. He passes away two days later... Abram is a counselor trained in a national ministry program who sees his volunteer work as part of his own growth. Behind bars since the early 1990s for murder, he has gotten used to spending time with male prison friends as they die in rooms 205 or 206 on the second floor of the state's prison for chronically ill inmates. In Ohio and nationally, the inmate population is graying. Ohio had 8,558 inmates over 50 this year, nearly double the number in 2001. Other states, including Louisiana, Iowa and California, have similar prison programs. <http://www.seattlepi.com/news/medical/article/Inmates-help-other-prisoners-face-death-in-6553561.php>

### **Prison Hospice Backgrounder**

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

### **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.18.

## DC's 16-week family leave plan would be most generous in U.S.

WASHINGTON DC | *The Washington Post* – 5 October 2015 – The District would become the most generous place in the country for a worker to take time off after giving birth or to care for a dying parent under a measure supported by a majority of the DC Council. Under the legislation ... almost every part-time and full-time employee in the nation's capital would be entitled to sixteen weeks of paid family leave to bond with an infant or an adopted child, recover from an illness, recuperate from a military deployment or tend to an ill family member. The broad new worker benefit, enthusiastically supported by the Obama administration, would be paid from a fund created by a new tax on DC employers. The benefit would dwarf family-leave assistance in all 50 states and would also mark a step to-

ward benefits offered by most European countries, where parents can take as much as a year of paid time off following the birth of a child. [https://www.washingtonpost.com/local/dc-politics/dc-could-become-best-place-in-us-to-have-a-baby-get-sick-or-have-parents/2015/10/05/0277c3ae-6b30-11e5-aa5b-f78a98956699\\_story.html](https://www.washingtonpost.com/local/dc-politics/dc-could-become-best-place-in-us-to-have-a-baby-get-sick-or-have-parents/2015/10/05/0277c3ae-6b30-11e5-aa5b-f78a98956699_story.html)

### Specialist Publications

'Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study' (p.9), in *BMC Medicine*.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *The Los Angeles Times* – 7 October 2015 – '**California coroners have issues with new assisted death law.**' A group representing county coroners in California says several problems need to be addressed in the new assisted-death law signed this week by Governor Jerry Brown. "We have a lot of concerns about the language," said Rocky Shaw, a supervising investigator for San Bernardino County and president of the California State Coroners Association. "There are a lot of details to be worked out." One is what to list on death certificates as the immediate cause of death. In the past, someone taking a lethal dose of drugs would be ruled a suicide, but the new law says that "death resulting from the self-administration of an aid-in-dying drug is not suicide." Shaw said that leaves a question about how to classify such a death. <http://www.latimes.com/local/political/la-me-pc-california-coroners-have-issues-with-new-assisted-suicide-law-20151006-story.html>
- CALIFORNIA | *The Los Angeles Times* – 6 October 2015 – '**Governor Brown signs controversial assisted-suicide bill.**' Caught between conflicting moral arguments, Governor Jerry Brown, a former Jesuit seminary student, signed a measure allowing physicians to prescribe lethal doses of drugs to terminally ill patients who want to hasten their deaths. <http://www.latimes.com/local/political/la-me-pc-gov-brown-end-of-life-bill-20151005-story.html>

## International

### Palliative services to be reinstated in South Australia's south-east after local lobbying

AUSTRALIA (South Australia) | ABC News – 6 October 2015 – Palliative care services cut in South Australia's south-east will be reinstated by the State Government following a hard-fought campaign by the local community. Health Minister Jack Snelling said the roles [i.e., the services] were cut from the south-east region from July 1 because of an end to Federal Government funding. He said he made a decision to reinstate the roles after meeting last week with a south-east lobby group campaigning against the cuts. He also met with nurses at Mt Gambier Hospital whom he said convinced him to bring back the services. <http://www.abc.net.au/news/2015-10-06/palliative-care-services-to-be-reinstated-in-sas-south-east/6831814>

**N.B.** Australia was ranked 2nd of the 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](http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf)

## 2015 Quality of Death Index

### U.K. end-of-life care “best in world”

U.K. | BBC News – 6 October 2015 – End-of-life care in the U.K. has been ranked as the best in the world with a study praising the quality and availability of services.<sup>1</sup> The study of 80 countries said thanks to the National Health Service and hospice movement the care provided was “second to none.” Rich nations tended to perform the best – with Australia and New Zealand ranked second and third respectively. But the report by the Economist Intelligence Unit praised progress made in some of the poorest countries. For example Mongolia – ranked 28th – has invested in hospice facilities, while Uganda – 35th – has managed to improve access to pain control through a public-private partnership. The rankings were worked out following assessments for the quality of the hospitals and hospice environments, staffing numbers and skills, affordability of care and quality of care. Just 34 out of 80 countries provided what could be classed as good end-of-life care – and these accounted for just 15% of the adult population. The report said the quality of end-of-life care was becoming increasingly important with the ageing population, meaning people were increasingly facing “drawn-out” deaths. Overall, the U.K. was given 93.9 out of 100, but the report still said there was room for improvement – as there was with all the top-performing nations. Services in England have recently been criticised by the Parliamentary & Health Service Ombudsman.<sup>2</sup> <http://www.bbc.com/news/health-34415362>

### End-of-Life Care: The Best and the Worst

Top 10	Score out of 100	Bottom 10	Score out of 100
UK	93.9	Iraq	12.5
Australia	91.6	Bangladesh	14.1
New Zealand	87.6	Philippines	15.3
Ireland	85.8	Nigeria	16.9
Belgium	84.5	Myanmar	17.1
Taiwan	83.1	Dominic Republic	17.2
Germany	82	Guatemala	20.9
Netherlands	80.9	Iran	21.2
US	80.8	Botswana	22.8
France	79.4	China	23.3

#### Extract from 2015 Quality of Death Index (p.19)

##### Palliative care in Mongolia

*When in 2000 the Mongolian Palliative Care Society was established, it marked the start of efforts to fill a gaping hole in palliative care services. Until then, the country had no hospices or palliative care teaching programmes ... and no government policy on palliative care existed.*

*Palliative care is ... now included in Mongolia's health and social welfare legislation and its national cancer control program. Since 2005, all medical schools and social workers receive palliative care training. And, since 2006, affordable morphine has been available.*

1. '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](http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf)

**N.B.** The study was commissioned by the philanthropic organization The Lien Foundation, of Singapore. Scroll down to p.19 of this issue of Media Watch for 'Quality of Death Index – Overall Scores' of the 80 countries surveyed. The Economist Intelligence Unit's 2010 quality of death index, also commissioned by the Lien Foundation, was noted in the issue of Media Watch of 19 July 2010, #158 (p.3), and can be downloaded at: [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf)

2. 'Dying Without Dignity: Investigations by the Parliamentary & Health Service Ombudsman into Complaints About End-of-Life Care,' May 2015. [Noted in Media Watch, 25 May 2015, #411 (p.6)] [http://www.ombudsman.org.uk/\\_data/assets/pdf\\_file/0019/32167/Dying\\_without\\_dignity\\_report.pdf](http://www.ombudsman.org.uk/_data/assets/pdf_file/0019/32167/Dying_without_dignity_report.pdf)

**N.B.** New 'End-of-Life Care Profiles,' developed by Public Health England's National End-of-Life Care Intelligence Team, provide a snapshot overview for each Government Office Region, Strategic Clinical Network, clinical commissioning group, and upper and lower tier local authorities. They are intended to help local government and health services improve care at the end of life, and provide comparative information on place of death by age. <http://fingertips.phe.org.uk/profile/end-of-life>

Cont.

Related:

- U.K. (England) | BBC News – 10 October 2015 – **‘Hospice inspections show most are “good” or “outstanding.”**’ More than 90% of England's hospices inspected so far have been rated as “good” or “outstanding,” the care watchdog said. The ratings come a year after the Care Quality Commission (CQC) introduced more rigorous assessments. Andrea Sutcliffe, its chief inspector of adult social care, said the results were “encouraging” and “what people deserve” at the end of their lives. So far, 37 hospice services have been inspected, out of a total of 324. Of those, 10 were judged “outstanding,” 24 were “good” and two were in the “requires improvement” category. The CQC is due to have reviewed all 25,000 adult social care services, including the further 287 hospice and hospice home-care services, by September 2016. <http://www.bbc.com/news/health-34493859>

**N.B.** Care Quality Commission website: <http://www.cqc.org.uk/content/most-hospices-are-%E2%80%98good%E2%80%99-or-better-says-cqc>

### **Home care in the U.K.**

#### **Crisis in home care for the elderly sees thousands going hungry: Estimated 40,000 say meals are inadequate leading to malnourishment fears**

U.K. (England) | *The Daily Mail* – 6 October 2015 – Thousands of elderly people receiving care at home are not being given enough to eat or drink, stark figures reveal. An estimated 40,000 say meals are inadequate or provided very late in the day, leading to worries they are becoming malnourished. Figures also show councils are rejecting almost two-thirds of requests from the elderly or vulnerable adults for extra care and support at home. Last year local authorities turned down 59% of the 1.85 million applications for help with daily tasks or equipment to help them around the home. Data from three separate reports from the Health & Social Care Information Centre also shows the elderly are increasingly having to stay in hospital unnecessarily because of a lack of care at home. The rate of delayed discharges – also referred to as bed-blocking – has increased by 15% in the 12 months between 2013-2014 and 2014-2015. Charities said the reports were further evidence of how the desperate shortfall in council funding was directly affecting the elderly. <http://www.dailymail.co.uk/news/article-3262727/Crisis-home-care-elderly-sees-thousands-going-hungry-Estimated-40-000-say-meals-inadequate-leading-malnourishment-fears.html>

**N.B.** Health & Social Care Information Centre reports:

1. ‘Community Care Statistics, Social Services Activity, England – 2014-2015’  
<http://www.hscic.gov.uk/catalogue/PUB18663>
2. ‘Measures from the Adult Social Care Outcomes Framework, England – 2014-2015’  
<http://www.hscic.gov.uk/catalogue/PUB18657>
3. ‘Personal Social Services Adult Social Care Survey, England – 2014-2015’  
<http://www.hscic.gov.uk/catalogue/PUB18642>

### **Cost of dying in the U.K.**

#### **Cost of a funeral soars to £3,700 – but what do you get?**

U.K. | BBC News – 4 October 2015 – One in ten people in the U.K. are struggling to pay for a funeral, according to a report seen by [BBC’s] ‘5 Live Investigates.’<sup>1</sup> Life and pensions group Royal London says the average cost of a funeral in the U.K. has risen by nearly 4% in the last year to £3,700, while the U.K. inflation rate has hovered around zero.<sup>2</sup> It wants policymakers to investigate the causes of rising funeral costs and better government help for people on low incomes. The Department of Work & Pensions says the average payment from its Social Fund scheme has increased year-on-year. So what does £3700 buy you? Only the most basic of funerals. Funeral director fees make up the majority of the cost and their prices have gone up by 5% on average. <http://www.bbc.com/news/business-34424586>

1. ‘5 Live Investigates’ episode on funeral costs: <http://www.bbc.co.uk/programmes/b06fjilly>

Cont.

2. Funeral costs in the U.K., Royal London National Funeral Cost Index 2015, Accessed 5 October 2015. <http://www.royallondon.com/products/over50s/aboutover50s/helpforyourfamily/averagefuneralcostcalculator/>

Related:

- U.K. (Scotland) | *The Daily Record* (Glasgow) – 5 October 2015 – ‘**Scottish Government orders probe into rising funeral costs...**’ John Birrell, chair of the Scottish working group on funeral poverty, has been appointed to work with Citizens Advice Scotland to come up with recommendations to address the issue [of rising funeral costs]. <http://www.dailyrecord.co.uk/news/scottish-news/scottish-government-orders-probe-rising-6577915>

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

- U.K. | *The Daily Mirror* – 29 March 2015 – ‘**Too poor to die – the shocking story of families who can’t afford to bury their loved ones.**’ Figures show an incredible 305,840 applications were made for funeral payments in Great Britain over the past five years. Of those almost 160,000 were accepted as soaring funeral costs leave hard-pressed families dependent on the local council to bury their loved ones. In the last 10 years the Government spent nearly £400 million paying for the funerals of people too poor to be buried otherwise. Last year alone the bill for paupers’ burials was an enormous £36 million pounds. <http://www.mirror.co.uk/news/uk-news/poor-die---shocking-story-5419973>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | *Dutch News* – 7 October 2015 – ‘**Euthanasia death total rises 10% in 2014.**’ There was a 10% rise in the number of euthanasia cases in The Netherlands last year, taking the total to 5,306, according to the regional euthanasia monitoring board. The number of cases has risen by around 10% a year for some time. In almost three in four cases, the patient had terminal cancer. <http://www.dutchnews.nl/news/archives/2015/10/euthanasia-death-total-rises-10-in-2014/>

**N.B.** The Netherlands was ranked 8th of the 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](http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf)

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- 2014, July - December
- 2014, January - June
- 2013, July - December
- 2013, January - June
- 2012, July - December
- 2012, January - June
- 2011, July - December
- 2011, January - June
- Current

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- 2014, July - December
- 2014, January - June
- 2013, July - December
- 2013, January - June
- 2012, July - December
- 2012, January - June
- 2011, July - December
- 2011, January - June
- Current

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



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

### Is home always the best and preferred place of death?

*BRITISH MEDICAL JOURNAL* | Online – 7 October 2015 – Focusing on place of death as the key indicator of quality in end-of-life care distracts attention from the experience of dying for patients and their families. Evidence suggests that place of death is not the over-riding priority. Control of symptoms, especially pain, and being accompanied by loved ones are more important. Much greater understanding of patient and public experience and attitudes to death and dying is needed, including where this should occur. When patients wish to die at home, every effort should be made to achieve this outcome. However, until resources are in place to adequately and equitably support home deaths, the current promotion of patient choice risks raising expectations that are not realised. There are many reasons why patients may not wish to die at home. Death at home is not necessarily good, and 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. When home death be-

comes normatively prescribed there is a risk that it becomes increasingly difficult for patients to express alternative preferences. Patients may be offered choice but be expected to “choose wisely.” Rather than reflecting prior and clearly articulated positions, patients’ recorded preferences may become co-constructed artefacts of a discussion shaped by professional perspectives and agendas. However well intentioned, these are inevitably influenced by pressure to achieve performance indicators for quality of care. Normalising home as the best and natural place to die promotes a sense of guilt and failure if death occurs elsewhere. The cultural script about death and dying risks being rewritten to promote ostensive choice as *de facto* obligation. <http://www.bmj.com/content/351/bmj.h4855>

#### Extract from *British Medical Journal* article

Given the projected increase in institutional deaths, the hospital needs to be reinvented as a viable alternative and place of excellent care for dying patients and their families.

Related:

- *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. The propensity of death at home also increased when the relative was aware of incurability and the patient discussed his/her preferences with family. Dying in hospital was associated with more hospital days, fewer general practitioner (GP) home visits, and fewer days taken off work by relatives. Adjusting for confounders, patients who died at home experienced similar pain levels but more peace in their last week of life... Grief was less intense for their relatives than for those of patients who died in hospital... <http://www.biomedcentral.com/1741-7015/13/235/abstract>

**N.B.** ‘Home death is associated with better patient and caregiver outcomes...’ Policy Brief (published in association with the above article), Cicely Saunders Institute, King’s College London, October 2015 <http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/research/studies/qualitycare/QUALYCARE-Policy-Brief.pdf>

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 of ... is that thousands of people are admitted to hospital every day, and culture and systems make it very difficult to escape. Studies have suggested that many who are in hospital could be supported elsewhere – however, this depends on citizens, health services and social care working much more cohesively together. <http://pmj.sagepub.com/content/early/2015/08/28/0269216315600996.full>

**A consensus review on the development of palliative care for patients with chronic and progressive neurological disease**

*EUROPEAN JOURNAL OF NEUROLOGY* | Online – 1 October 2015 – The European Association of Palliative Care Taskforce, in collaboration with the Scientific Panel on Palliative Care in Neurology of the European Federation of Neurological Societies (now the European Academy of Neurology), aimed to ... establish an evidence-based consensus for palliative and end-of-life care for patients with progressive neurological disease... There is limited evidence to support the recommendations, but there is increasing evidence that palliative care (PC) and a multidisciplinary approach to care do lead to improved symptoms and quality of life of patients and their families. The main areas in which consensus was found and recommendations could be made are in the early integration of PC, involvement of the wider multidisciplinary team, communication with patients and families including advance care planning, symptom management, end-of-life care, carer support and training, and education for all professionals involved in the care of these patients and families. There is a pressing need for increased collaboration between neurology and PC. <http://onlinelibrary.wiley.com/doi/10.1111/ene.12889/abstract?userIsAuthenticated=false&deniedAccessCustomisedMessage=>

Noted in Media Watch, 15 June 2015, #414 (p.15):

- *PROGRESS IN PALLIATIVE CARE* | Online – 6 June 2015 – ‘**The palliative care needs of people severely affected by neurodegenerative disorders: A qualitative study.**’ 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>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 October 2015 – ‘**End-of-life care of patients with amyotrophic lateral sclerosis and other non-malignant diseases.**’ Respiratory symptoms are important in the management of non-malignant diseases in hospice. Especially, units taking care of ALS should be prepared to meet the special needs involved in ventilation support. In contrast to ALS, late referrals to hospice are common in patients with other non-malignant diseases. <http://ajh.sagepub.com/content/early/2015/10/07/1049909115610078.abstract>
- *MULTIPLE SCLEROSIS* | Online – 7 October 2015 – ‘**Opening locked doors: Integrating a palliative care approach into the management of patients with severe multiple sclerosis.**’ Although initially counterintuitive, specialized palliative care (PC) may be beneficial for these patients and their relatives. Studies have shown that misunderstandings and a lack of information among healthcare professionals about the roles and services of PC for multiple sclerosis (MS) are still prevalent. This topical review will give an overview of the unmet needs of patients as well as the possible benefits and barriers of PC for MS... <http://msj.sagepub.com/content/early/2015/10/05/1352458515608262.abstract>

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

**[Media Watch: Palliative Care Network-e Website](http://www.pcn-e.com/community/pg/file/owner/MediaWatch)**

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>

## **Negotiating the equivocality of palliative care: A grounded theory of team communicative processes in inpatient medicine**

*HEALTH COMMUNICATION* | Online – 2 October 2015 – In the majority of U.S. hospitals, inpatient medicine teams make palliative care decisions in the absence of a formalized palliative system. Interviews with inpatient team members were systematically analyzed to uncover how participants conceptualize palliative care and how they regard the communicative structures that underlie its delivery. The 39 participant inpatient team members discussed palliative care as primarily a communicative process. Themes describing the meaning of palliative care emerged around the concepts of receiver of care, timeline of care, and location of care. The emerging model included four stages in the communicative processes of inpatient palliative care: 1) Interpret the need; 2) Initiate the conversation; 3) Integrate the processes; and, 4) Identify what works. In contrast to stable, focused palliative care teams or hospice care teams, which have prescribed patient populations and processes, the inpatient medicine team faces the equivocality of providing palliative care within a broader practice. This research offers a four-phase model to show how these inpatient teams communicate within this context. Implications for the provision of palliative care are discussed. <http://www.tandfonline.com/doi/abs/10.1080/10410236.2014.974134>

## **The gap between policy and practice: A systematic review of patient-centred care interventions in chronic heart failure**

*HEART FAILURE REVIEWS* | Online – 5 October 2015 – Patient-centred care (PCC) is recommended in policy documents for chronic heart failure (CHF) service provision, yet it lacks an agreed definition. A systematic review was conducted to identify PCC interventions in CHF and to describe the PCC domains and outcomes. Of 13,944 screened citations, 15 articles regarding 10 studies were included involving 2,540 CHF patients. Three studies were randomised controlled trials, and seven were non-randomised studies. PCC interventions focused on collaborative goal setting between patients and healthcare professionals regarding immediate clinical choices and future care. Core domains included healthcare professional-patient collaboration, identification of patient preferences, patient-identified goals and patient motivation. While the strength of evidence is poor, PCC has been shown to reduce symptom burden, improve health-related quality of life, reduce readmission rates and enhance patient engagement for patients with CHF. There is a small but growing body of evidence, which demonstrates the benefits of a PCC approach to care for CHF patients. <http://link.springer.com/article/10.1007/s10741-015-9508-5>

Noted in Media Watch, 13 July 2015, #418 (p.10):

- *AMERICAN HEART JOURNAL* | Online – 2 July 2015 – ‘**Unique challenges of hospice for patients with heart failure: A qualitative study of hospice clinicians.**’ From a hospice clinician perspective, caring for patients with heart failure is unique compared to other hospice populations. This study suggests potential opportunities for hospice clinicians and referring providers who seek to collaborate to improve care for patients with heart failure during the transition to hospice care. [http://www.ahjonline.com/article/S0002-8703\(15\)00393-2/abstract](http://www.ahjonline.com/article/S0002-8703(15)00393-2/abstract)
- *BRITISH JOURNAL OF CARDIAC NURSING* | Online – 3 July 2015 – ‘**Understanding palliative care needs in heart failure.**’ Clinicians often struggled to discuss palliation with heart failure patients owing to the unclear disease trajectory and cardiac-specific barriers to identifying palliation needs. <http://www.magonlinelibrary.com/doi/abs/10.12968/bjca.2015.10.7.348>
- *HEART FAILURE CLINICS*, 2015;11(3):479-498. ‘**Team-based palliative and end-of-life care for heart failure.**’ Clinical practice guidelines endorse the use of palliative care in patients with symptomatic heart failure. The optimal content and delivery of palliative care interventions remains unknown and its integration into existing heart failure disease management continues to be a challenge. [http://www.heartfailure.theclinics.com/article/S1551-7136\(15\)00024-0/abstract](http://www.heartfailure.theclinics.com/article/S1551-7136(15)00024-0/abstract)

**N.B.** Additional articles on palliative care in patients with heart failure noted in past issues of Media Watch are listed in the issue of the weekly report dated 19 January 2015, #393 (pp.11-12).

### **What do we need at the end of life? Competence, but not autonomy, predicts intraindividual fluctuations in subjective well-being in very old age**

*JOURNALS OF GERONTOLOGY* | Online – 7 October 2015 – Self-determination theory (SDT) suggests fulfillment of the universal psychological needs for autonomy, competence and relatedness is essential for well-being of all humans. However, it is not clear whether this prediction also holds in advanced old age. 111 very old adults (age range at first measurement occasion 87-97 years) were assessed up to 6 times over the course of about 4 years. Competence, but not autonomy, predicted subjective well-being at the within-person level of analysis. At the between-person level, only negative affect was predicted by autonomy and competence, whereas positive affect and life satisfaction were predicted by competence only. <http://psychogerontology.oxfordjournals.org/content/early/2015/10/07/geronb.gbv052.abstract>

### **Wisdom at the end of life: An analysis of mediating and moderating relations between wisdom and subjective well-being**

*JOURNALS OF GERONTOLOGY* | Online – 5 October 2015 – This study investigated whether wisdom might be particularly beneficial for people at the end of life, when extrinsic means to increase well-being largely disappear, and whether the association between wisdom and well-being is mediated by mastery and purpose in life. Wisdom was positively related to subjective well-being in the later years, even after controlling for physical health, socioeconomic status, financial situation, social involvement, age, gender, race, and marital status. The association between wisdom and well-being was significantly stronger in the nursing home and hospice sample than the community sample. The relation between wisdom and well-being was partially mediated by purpose in life, both directly and via a sense of mastery. <http://psychogerontology.oxfordjournals.org/content/early/2015/10/05/geronb.gbv051.abstract>

### **Improving caregivers' perceptions regarding patient goals of care/end-of-life issues for the multidisciplinary critical care team**

*JOURNAL OF INTENSIVE CARE MEDICINE* | Online – 28 September 2015 – The authors created a novel unit-based multidisciplinary program for improved goals of care/end-of-life (GOC/EOL) approaches in the critical care setting. A similarly formatted program could be adapted by other ICUs. Benefits of such a program include improving caregivers' perceptions regarding EOL/GOC issues and fostering critical care team growth. <http://jic.sagepub.com/content/early/2015/09/24/0885066615606063.abstract>

Noted in Media Watch, 21 September 2015, #428 (p.8):

- *AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE* | Online – 17 September 2015 – '**Randomized trial of communication facilitators to reduce family distress and intensity of end-of-life care.**' This is the first study [i.e., a randomized trial at two hospitals] to find a reduction in intensity of end-of-life care and improved family distress. Facilitators supported communication between clinicians and families, adapted communication to family needs, and mediated conflict. <http://www.atsjournals.org/doi/abs/10.1164/rccm.201505-0900OC#.VfwSsc9RGos>

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

- *AMERICAN JOURNAL OF CRITICAL CARE*, 2014;23(5):380-386. '**Clinicians' perceptions of the usefulness of a communication facilitator in the intensive care unit.**' Clinicians (i.e., study participants) perceived facilitators as 1) Facilitating communication between patients' families and clinicians; 2) Providing practical and emotional support for patients' families; and, 3) Providing practical and emotional support for clinicians. Clinicians were enthusiastic about the communication facilitator, but concerned about overlapping or conflicting roles. <http://ajcc.aacnjournals.org/content/23/5/380.short>

## Nursing perspectives on end-of-life care

### **Palliative care nursing in Cyprus**

*JOURNAL OF PALLIATIVE CARE & MEDICINE* | Online – 25 September 2015 – Palliative homecare in the Republic of Cyprus is limited to cancer patients and only provided by two non-governmental organizations, which offer free services to adults. Nurses employed by these charities support patients and assist families in the provision of necessary care. They play a vital role in helping to improve quality of life, using a holistic approach when addressing issues of concern and when helping to overcome the difficulties which may arise from pain and other symptoms. They advocate best practice and strive to educate, not only patients and their care givers, but also other healthcare professionals and the general public, in an effort to empower, ensure safety and promote good palliative care. Although these services have evolved since their onset in the 1980s there is a continuing need for improvement and expansion in order to ensure that 24 hour care is available for all, both adults and children, regardless of disease. <http://www.omicsgroup.org/journals/palliative-care-nursing-in-cyprus-2165-7386-1000S4006.pdf>

Noted in Media Watch, 11 April 2011, #196 (p.10):

- *JOURNAL OF PEDIATRIC HEMATOLOGY/ONCOLOGY*, 2011;30(Supple1-80). ‘**Palliative care in Middle-Eastern countries.**’ The focus of this article is on palliative care in Cyprus, Egypt, Israel, Pakistan, the Palestinian Authority and Turkey. <http://journals.lww.com/jpho-online/toc/2011/04001>

Related:

- *JOURNAL OF EMERGENCY NURSING* | Online – 3 October 2015 – ‘**When someone dies in the emergency department: Perspectives of emergency nurses.**’ Analysis [of the interviews conducted with emergency department nurses from a large Canadian academic health sciences system] resulted in 3 major themes: 1) “It’s not a nice place to die,” 2) “I see the grief,” and 3) “Needing to know you’ve done your best.” Findings revealed that emergency nurses believed the environment made it difficult to care for dying patients and their families because of unpredictability, busyness, noise, lack of privacy, and the need to manage many patients simultaneously. These nurses were also put in the position of caring for the suddenly bereaved family members, which was viewed as an especially challenging aspect of their role. <http://www.sciencedirect.com/science/article/pii/S0099176715004481>

### **It was as good as it could be – A family member’s non-experiences of guilt and shame in end-of-life care**

*JOURNAL OF PALLIATIVE CARE & MEDICINE*, 2015;5(5). The aim of this study was to explore and interpret a family member’s situation without feelings of guilt and shame and describe reasons for non-experiences of these feelings. Seven sub-themes appeared: 1) “The mother received good care with clear planning”; 2) “They became aware of the inevitable death”; 3) “The mother knew how she wanted things to be”; 4) “Mutual understanding and care between mother and daughter”; 5) “They could make the most of the time that was left”; 6) “The family was together during the dying”; and, “Both the daughter and her mother could handle and see meaning in the situation.” These sub-themes resulted in a main theme: “There wasn’t much we could have done differently. It was as good as it could be.” Three interpretations emerged that can decrease the risk of feelings of guilt and shame: 1) Knowing that the loved one is receiving professional care of good quality; 2) Family awareness of the situation and trusting and supportive relationship with the professionals; and, 3) inner and external resources and open communication with each other. The study shows the importance of professionals being involved in the family situation, having the courage to be sensitive towards the patient’s and the family member’s requests in situations where there is dying and death. Being aware of the suggested interpretations can decrease the risk of feelings of guilt and shame. <http://www.omicsgroup.org/journals/it-was-as-good-as-it-could-be-a-family-members-nonexperiences-of-guiltand-shame-in-endoflife-care-2165-7386-1000232.pdf>

## Talking about death with children with incurable cancer: Perspectives from parents

*JOURNAL OF PEDIATRICS* | Online – 28 September 2015 – Most parents in this study cited several reasons for not discussing death with their child. The authors findings highlight the sensitive and complex issues surrounding these conversations, indicating that there may be a role for clinicians in supporting parents. They were asked whether they had discussed the impending death with their child, whether they reflected on this discussion positively, their reasons for not discussing death with their child, and the manner in which the conversation regarding death occurred. Of the 86 parents of 56 children who participated, 55 parents (of 35 children) did not discuss the impending death with their child. The themes identified: 1) Parents' inability to discuss the impending death; 2) Parents' desire to protect their child; 3) Views regarding talking with children; 4) Parents' views of child characteristics; 5) Child's unwillingness to

discuss the subject; 6) Lack of opportunity to talk; and, 7) Child's disability. The parents who did discuss death with their child generally used symbolic and/or religious narratives, or they had brief, direct conversations regarding death. [http://www.jpeds.com/article/S0022-3476\(15\)00999-3/abstract](http://www.jpeds.com/article/S0022-3476(15)00999-3/abstract)

### [Together for Short Lives Infographics](#)

An estimated 49,000 seriously ill children in the U.K. live with health or medical conditions that mean they may die young. The new infographics help to visualise the impact caring for a child with a life-limiting condition can have on families and loved ones. [http://www.togetherforshortlives.org.uk/news/8596\\_new\\_infographics\\_illustrate\\_how\\_we\\_are\\_here\\_for\\_the\\_49\\_000](http://www.togetherforshortlives.org.uk/news/8596_new_infographics_illustrate_how_we_are_here_for_the_49_000)

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 October 2015 – '**Pediatrician ambiguity in understanding palliative sedation at the end of life.**' Pediatricians [i.e., survey respondents] were concerned with a decreased level of consciousness as the goal of palliative sedation. Respondents were split on whether they view palliative sedation as a distinct entity or as one broad continuum of care, equivalent to aggressive symptom management. Institutional-based policies are essential to clarify acceptable practice, enable open communication, and promote further research. <http://ajh.sagepub.com/content/early/2015/10/05/1049909115609294.abstract>

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

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – '**Palliative sedation: Analysis of international guidelines...**' Published guidelines: American College of Physicians-American Society of Internal Medicine (2000), Hospice & Palliative Nurses Association (2003), American Academy of Hospice & Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice & Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). <http://ajh.sagepub.com/content/early/2014/05/06/1049909114533002.abstract>
- *NURSING CHILDREN & YOUNG PEOPLE*, 2015;27(8):20-24. '**Parents' experiences of care decisions about children with life-limiting illnesses.**' Parents [i.e., study participants] understand the importance of planning for the end of their child's life, but find the process difficult. They also find it a challenge to verbalise their decisions ... and value having the decision partly taken away from them. Professionals can assist parents by using a non-dissent model of decision making. The parents' values are important in these decisions and should be elicited by professionals during the initial stages of decision making. <http://journals.rcni.com/doi/abs/10.7748/ncyp.27.8.20.s23>
- *PEDIATRICS* | Online – 5 October 2015 – '**Hospital use in the last year of life for children with life-threatening complex chronic conditions.**' Although many adults experience resource-intensive and costly health care in the last year of life, less is known about these health care experiences in children with life-threatening complex chronic conditions (LT-CCCs). The authors assessed hospital resource use in children by type and number of LT-CCCs. Hospital use for children with LT-CCCs in the last year of life varies significantly across the type and number of conditions. Children with hematologic/immunologic or multiple conditions have the greatest hospital use. This information may be useful for clinicians striving to improve care for children with LT-CCCs nearing the end of life. <http://pediatrics.aappublications.org/content/early/2015/09/29/peds.2015-0260.abstract>

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

### **The impact of race on intensity of care provided to older adults in the medical intensive care unit**

*JOURNAL OF RACIAL & ETHNIC HEALTH DISPARITIES* | Online – 28 September 2015 – African Americans and Hispanics receive disproportionately less aggressive non-critical treatment for chronic diseases than their Caucasian counterparts. However, when it comes to end-of-life care, minority races are purportedly treated more aggressively in Medical Intensive Care Units (MICU) and are more likely to die there. Although prior studies have reported that non-white populations often opt for more aggressive care, the similar proportions of non-white and white “full code” patients in this study suggests that this idea is overly simplistic. <http://link.springer.com/article/10.1007/s40615-015-0162-3/fulltext.html>

Noted in Media Watch, 5 January 2015, #391 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 December 2014 – ‘**End-of-life care for people with cancer from ethnic minority groups: A systematic review.**’ Twenty-five studies were included: 20 quantitative and five qualitative. All focused on the ethnic/racial minority groups of African Americans, Hispanics Americans, or Asian Americans. African Americans perceived a greater need for hospice, yet more frequently had inadequate knowledge. African Americans preferred aggressive treatment, yet end-of-life care provided was often inconsistent with preferences <http://ajh.sagepub.com/content/early/2014/12/29/1049909114565658.abstract>

**N.B.** The U.S. was ranked 9th of the 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](http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf)

### **A cross-cultural study on behaviors when death is approaching in East Asian countries: What are the physician-perceived common beliefs and practices?**

*MEDICINE*, 2015;94(39):e1573. Five-hundred-and-five, 211 and 207 responses were obtained from Japanese, [South] Korean, and Taiwan physicians, respectively. While 50% of the Japanese physicians reported they often or very often experienced families as being reluctant to discuss end-of-life issues, the corresponding figures were 59% in [South] Korea and 70% in Taiwan. Two specific reasons to avoid end-of-life discussions – “bad things happen after you say them out loud” and “a bad life is better than a good death” – were significantly more frequently observed in Taiwan. Prioritizing the oldest of the family in breaking bad news and having all family members present at the time of death were significantly more frequently observed in [South] Korea and Taiwan. Half of Taiwanese physicians reported they often or very often experienced the patients/family wanted to go back home to die because the soul would not be able to return from the hospital. In all countries, more than 70% of the physicians reported certain family members were expected to care for the patient at home. At the time of death, while no Japanese physicians stated they often experienced patients wanted a religious person to visit, the corresponding figure in [South] Korea and Tai-

wan was about 40%. Uncovered expression of emotion was frequently observed in [South] Korea and Taiwan, and 42% of the Japanese physicians reported that family members cleaned the dead body of the patient themselves. <http://www.ncbi.nlm.nih.gov/pubmed/26426631>

#### **2015 Quality of Death Index (pp.49-50)**

##### **Case study: Taiwan – Leading the way**

Taiwan ranks near the top ... coming first in Asia and sixth overall. Its high position is the result of a number of factors. Firstly, the availability of palliative services has steadily grown in recent years, with hospice programs increasing more than 50% to 77 program during 2004-2012, and hospital-based palliative care teams multiplying from 8 to 69.

**Footnotes:** Japan was ranked 14th and South Korea 18th, respectively, of the 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](http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf)

Chinese language edition:

<http://www.economistsinsights.com/sites/default/files/2015%20Quality%20of%20Death%20Index%20FINAL%20SC.pdf>

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

### **New guidelines for primary palliative care in oncology**

MEDSCAPE | Online – 8 October 2015 – A new guidance statement to define high-quality primary palliative care delivery in medical oncology has been developed by the American Society of Clinical Oncology (ASCO) and the American Academy of Hospice & Palliative Medicine. The two organizations have partnered to develop these recommendations to help medical oncology practices identify essential palliative care services and deliver high-quality primary palliative care to all patients with cancer. "This is an important first step to improve the palliative care that is directly delivered by oncologists," said lead study author Kathleen Bickel, MD, MPhil, an assistant professor of medicine at the White River Junction Veterans Affairs Medical Center and the Geisel School of Medicine at Dartmouth in Hanover, New Hampshire. Palliative care that is integrated in routine oncology care can improve symptom burden, quality of life, and patient and caregiver satisfaction. ASCO recommends concurrent use of palliative care with cancer care early in the course of illness for any patient with metastatic cancer and/or high symptom burden. However, not all patients with cancer have access to experts in palliative medicine, said Dr Bickel. "The small workforce of palliative care specialists is insufficient to meet the needs of all cancer patients who might benefit from palliative care services across the US. Thus, alternative models are being sought." Although oncologists do already provide many palliative services, until now, there has been no comprehensive guidance for what practices should provide. <http://www.medscape.com/viewarticle/852423>

Related:

- *JAMA OTOLARYNGOLOGY HEAD & NECK SURGERY* | Online – 8 October 2015 – '**The cost of hospice services in terminally ill patients with head and neck cancer.**' Encouraging hospice admissions for patients with oral cavity and pharyngeal cancers provides not only compassionate, dignified care at the end of life but also an opportunity for substantial savings in health care costs. Patients who received hospice care had \$7,035 ... lower costs in the last month of life for oral cavity cancer and \$7,430 ... lower costs in the last month of life for pharyngeal cancer. These cost savings were greater in the last month of life when patients enrolled in hospice more than 30 days before death. <http://archotol.jamanetwork.com/article.aspx?articleid=2448771&resultClick=3>
- *JOURNAL OF THE NATIONAL CANCER INSTITUTE* | Online – 5 October 2015 – '**Hospice use among patients with lymphoma: Impact of disease aggressiveness and curability.**' Hospice use was substantially lower than the national average for all cancers, suggesting either the need for improvement in enrollment or that the current hospice model is not meeting this population's end-of-life needs. Moreover, the fact that patients with mantle cell lymphoma were most likely to enroll suggests that the end-of-life phase may be more easily determined in the context of cancers that are both aggressive and incurable. <http://jnci.oxfordjournals.org/content/108/1/djv280.short>

**N.B.** Selected articles on the integration of palliative care with oncology care are noted in Media Watch of 7 September 2015, #426 (pp.15-16), 30 March 2015, #403 (pp.15-16), and 22 December 2014, #389 (pp.14-15).

### **Spirituality in palliative care: Evidence of counselling**

*PSYCHOSOCIAL INTERVENTION*, 2015;24(2):79-82. When spiritual needs are effectively elaborated, they can help the individual to find meaning, sustain hope, and accept death in the context of the end of life. Counselling has been one of the therapies most used to meet these needs. The aim of this work is to offer evidence on the efficacy of this therapy to improve the spirituality of patients attended in several health devices. In order to achieve this objective, a three-week intervention was carried out with 131 home care and hospitalized patients. Results indicate a positive effect, with a large effect size. This study can be the starting point for the implementation of intervention programs in the context of palliative care. [http://apps.elsevier.es/watermark/ctl\\_servlet?f=10&pident\\_articulo=90435351&pident\\_usuario=0&pcontacitid=&pident\\_revista=362&ty=120&accion=L&origen=psyint&web=psychosocial-intervention.elsevier.es&lan=es&fichero=362v24n02a90435351pdf001.pdf](http://apps.elsevier.es/watermark/ctl_servlet?f=10&pident_articulo=90435351&pident_usuario=0&pcontacitid=&pident_revista=362&ty=120&accion=L&origen=psyint&web=psychosocial-intervention.elsevier.es&lan=es&fichero=362v24n02a90435351pdf001.pdf)

**N.B.** Spanish language article. Additional articles on spirituality in the context of end-of-life care are listed in this issue of Media Watch.



## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BIOETHICS* | Online – 8 October 2015 – ‘**On the moral acceptability of physician-assisted dying for non-autonomous psychiatric patients.**’ Several authors have recently suggested that the suffering caused by mental illness could provide moral grounds for physician-assisted dying. Yet they typically require that psychiatric-assisted dying could come to question in the cases of autonomous, or rational, psychiatric patients only. Given that also non-autonomous psychiatric patients can sometimes suffer unbearably, this limitation appears questionable. The author maintains that restricting psychiatric-assisted dying to autonomous, or rational, psychiatric patients would not be compatible with endorsing certain end-of-life practices commonly accepted in current medical ethics and law, practices often referred to as “passive euthanasia.” <http://onlinelibrary.wiley.com/doi/10.1111/bioe.12182/abstract>
- *JOURNAL OF CRIMINAL LAW*, 2015;79(5):358-372. ‘**Mercy killing: Three’s a crowd?**’ A defendant who has committed a so called “mercy killing,” meaning that they killed a loved one to end their suffering from some kind of painful or terminal illness or disease, has no direct route to a manslaughter conviction. It is a difficult situation for the courts, although such actions are acknowledged as a mitigating feature at the sentencing stage. This article discusses the controversial subject, and questions if it may be included within the scope of either diminished responsibility or loss of control since the [U.K.] Coroners & Justice Act 2009 came into force. <http://clj.sagepub.com/content/79/5/358.short>
- *SOUTHERN MEDICAL JOURNAL*, 2015;108(10):599-604. ‘**How does legalization of physician-assisted suicide affect rates of suicide?**’ Legalizing physician-assisted suicide (PAS) has been associated with an increased rate of total suicides relative to other states and no decrease in non-assisted suicides. This suggests either that PAS does not inhibit (nor acts as an alternative to) non-assisted suicide, or that it acts in this way in some individuals but is associated with an increased inclination to suicide in other individuals. <http://sma.org/southern-medical-journal/article/how-does-legalization-of-physician-assisted-suicide-affect-rates-of-suicide/>

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### Media Watch: Editorial Practice

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

### Distribution

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.

### Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### Something Missed or Overlooked?

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

- *TILBURG LAW REVIEW*, 2015;20(2):107-121. **'Methods of lawmaking of the European Court of Human Rights: Do hard cases make bad law?'** Different cases on euthanasia and assisted suicide and the reception of these cases are considered. The analysis demonstrates the Court appears to adhere to its established methods of interpretation when deciding cases concerning euthanasia and assisted suicide, particularly evidenced by the use of the margin of appreciation. When considering the application of the margin of appreciation by the Court in the selected cases, as well as the lack of consensus among Member States in these cases, it appears the Court's interpretations cannot be classified as bad law. <http://booksandjournals.brillonline.com/content/journals/10.1163/22112596-02002003>

### [Media Watch: Online](#)

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/publications/newsletter/2015/10/media-watch/>

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

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

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

#### **Asia**

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

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

#### **Australia**

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

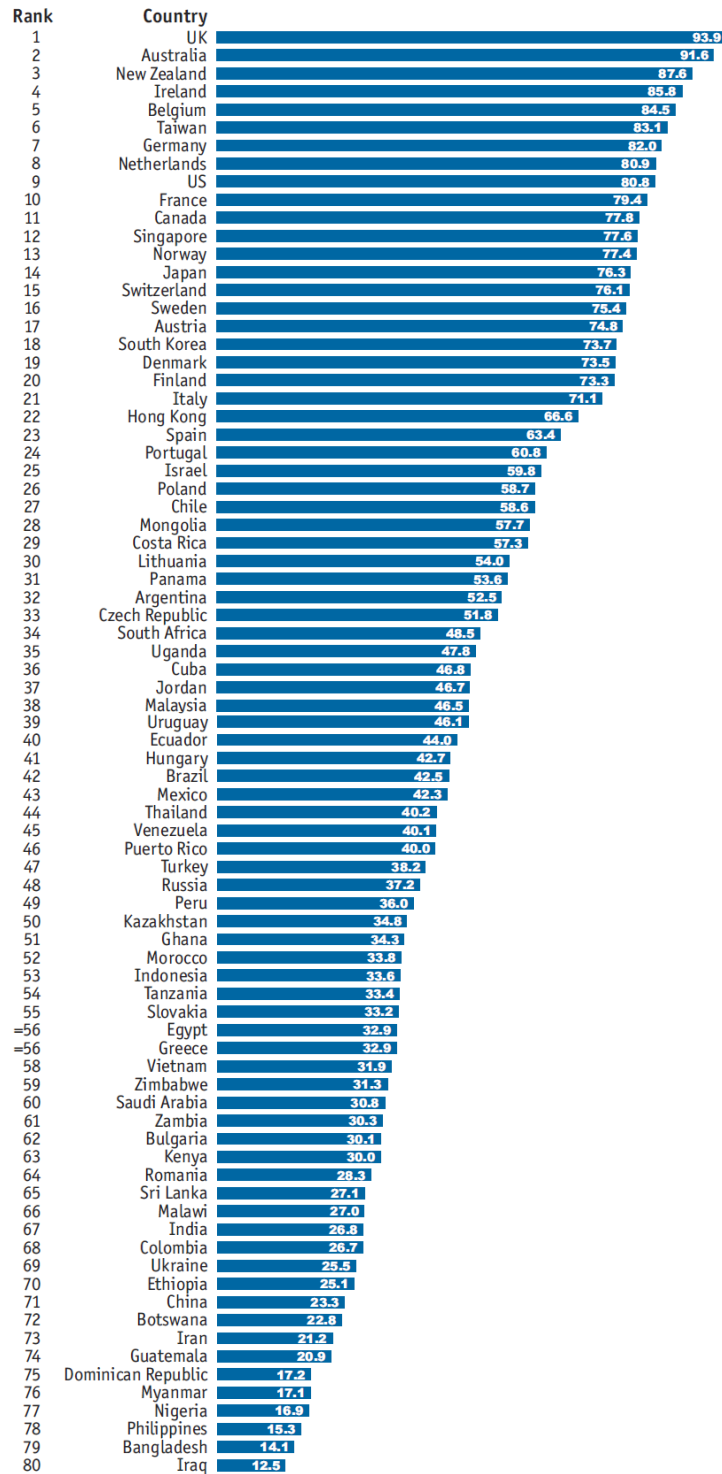
U.K. | Omega, the National Association for End-of-Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

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## The 2015 Quality of Death Index: Ranking Palliative Care Across the World

### 2015 Quality of Death Index—Overall scores



Economist Intelligence Unit

<http://www.economistinsights.com/healthcare/analysis/quality-death-index-2015>