

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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Searching for the evidence to support practice: Scroll down to [Specialist Publications](#) and 'How effective are palliative care clinicians in finding the evidence in their field?' (p.13), in *Health Information & Libraries Journal*.

Canada

Canadians not confident about future of seniors' health care: Polls

THE GLOBE & MAIL | Online – 24 August 2015 – Canadians are rapidly losing faith in the ability of the health system to provide care for their aging loved ones and they want the federal government to step up and find solutions, two new public opinion surveys show. Fewer than one in four believe there will be adequate home care and long-term care facilities, and just one in three think there will be sufficient hospital beds available to meet their basic medical needs as they age, according to a poll commissioned by the Canadian Medical Association (CMA).¹ At the same time, three in five of those surveyed do not feel they are in a good position – financially or otherwise – to care for aging family members in need of long-term health care. The CMA, which represents Canada's 80,000 physicians, residents and medical students, is holding its annual meeting in Halifax this week, and it is using the occasion to press all federal parties to commit to adopting a national strategy on seniors' care. "We don't want little election goodies with a seniors' theme; we want a commitment to a long-term strategic plan," Dr. Chris Simpson, president of the CMA, said in an interview. "Eve-

ryone already has horror stories in their families, and when they hear the doomsday stats, they really get worried about the future," Dr. Simpson said. "Seniors' health care is an issue that is really starting to resonate across the generations." A second poll, commissioned by the Canadian Alliance for Long Term Care, found 18% of citizens believe hospital and long-term care homes would be able to meet the needs of the aging population; only 20% think there will be enough trained staff to provide adequate care.² <http://www.theglobeandmail.com/news/national/canadians-not-confident-about-future-of-seniors-health-care-polls/article26067927/>

Extract from Ipsos report

Nine in ten Canadians (90%) agree that we need a national strategy on seniors' health care that addresses the need for care provided at home and in hospitals, hospices and long-term care facilities, as well as end-of-life care.

Cont.

1. 'Three in five Canadians aren't prepared to care for family members who require long-term care,' Ipsos (Canada), 24 August 2015. <http://www.ipsos-na.com/news-polls/pressrelease.aspx?id=6959>
2. 'Gauging Canadians' Impressions of Long Term Care in Canada' (Summary), Nanos Research, July 2015. <http://www.nanosresearch.com/main.asp>

Related:

- CTV NEWS | Online – 24 August 2015 – '**Canadian Medical Association calls for national seniors strategy.**' The Canadian Medical Association says it has laid out a framework to address the growing health care needs of Canadian seniors, which it says is one of the most pressing issues of our time. <http://atlantic.ctvnews.ca/canadian-medical-association-calls-for-national-seniors-strategy-1.2531490>
 1. 'A Policy Framework to Guide a National Seniors Strategy for Canada,' Canadian Medical association, August 2015. https://www.cma.ca/Assets/assets-library/document/en/about-us/gc2015/policy-framework-to-guide-seniors_en.pdf

Noted in Media Watch, 19 January 2015, #393 (p.1):

- *THE GLOBE & MAIL* | Online – 16 January 2015 – '**When a stagnant health system meets an aging population, disaster awaits.**' Since we are all going to get old and die one day, we have a stake in how well Canada's health-care system looks after senior citizens. The problem is, not many of us are confident that it's going well. The CMA released a poll in August [2014] in which Canadians expressed a sincere set of worries about their medical prospects in old age.¹ Four out of five said they aren't confident they'll be able to access the health services they will need. Three-quarters are worried they won't have the money to pay for services that aren't covered by medicare after they retire. And, 61% doubt the country's hospitals and long-term care facilities will be able to meet the demands of Canada's relentlessly aging population. <http://www.theglobeandmail.com/globe-debate/editorials/when-a-stagnant-health-system-meets-an-aging-population-disaster-awaits/article22487481/>
 1. '2014 National Report Card,' Canadian Medical Association, August 2014. [Noted in Media Watch, 25 August 2015, #372 (p.1)] https://www.cma.ca/En/Lists/Medias/2014_Report_Card-e.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE TORONTO STAR* | Online – 28 August 2015 – '**77% of Canadians support assisted suicide, poll shows.**' A large and growing majority of Canadians support physician assisted death, a new poll has found, even as many of the country's doctors report they would refuse to end a patient's life. According to a Forum poll ... 77% of the population believes in doctor-assisted suicide for people who are terminally ill, up 10% from a similar poll the firm conducted just four years ago. The poll results come the same week that the Canadian Medical Association released an internal survey that found 63% of its members wouldn't provide medical aid in dying to a patient who requested it. Twenty-nine per cent of respondents said they would. The survey ... is not considered a scientifically accurate reflection of how all Canadian doctors feel, but still suggests the medical community is divided on a practice that will become decriminalized in a matter of months. <http://www.thestar.com/news/gta/2015/08/28/77-of-canadians-support-assisted-suicide-poll-shows.html>

Cont. next page

[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.

- CTV NEWS | Online – 25 August 2015 – ‘**Doctors group looking at intensive course to train willing MDs in assisted death.**’ Doctors who are willing to assist in a patient’s death once the act becomes legal early next year will need to be trained because they’ve never been taught the procedures for ending a life, the Canadian Medical Association (CMA) says. “There’s a lot of complexity in this for Canadian doctors and it’s the first time really any of us can remember that (we) have been forced to undertake an entirely new procedure or new intervention without any training or experience,” Dr. Jeff Blackmer, vice-president of medical professionalism, told a media briefing during the CMA’s annual meeting in Halifax [see sidebar]. Blackmer said the 80,000-member doctors’ organization is considering an intensive two-day course for physicians “who have never had to learn this, who have not taken it in medical school or residency.” <http://www.ctvnews.ca/health/doctors-group-looking-at-intensive-course-to-train-willing-mds-in-assisted-death-1.2532609>



N.B. CMA’s ‘End-of-life care in Canada: A principles-based approach to assisted dying,’ August 2015. <http://www.slideshare.net/CanadianMedicalAssociation/strategic-session-on-endoflife-care-in-canada-dr-blackmer>

- *THE GLOBE & MAIL* | Online – 25 August 2015 – ‘**Less than a third of doctors willing to aid in assisted dying: CMA poll.**’ A significant minority of Canadian physicians – 29% – say they would be willing to assist a gravely ill patient who wants to end their life. But despite a Supreme Court of Canada ruling striking down the prohibition on assisted death, the majority of physicians, 63%, still want no part of it. Those numbers, from a poll of 1,403 doctors by the CMA, serve as a backdrop as the association tries to fashion its position on the complex, emotionally charged issue of physician-assisted death. <http://www.theglobeandmail.com/news/national/less-than-a-third-of-doctors-willing-to-participate-in-assisted-dying-poll/article26100505/>

U.S.A.

Life expectancy at birth

Who wants to live forever?

THE ECONOMIST | Online – 27 August 2015 – Statisticians at the Institute for Health Metrics and Evaluation at the University of Washington have calculated new figures that adjust life expectancy at birth for the number of healthy years that a person can be expected to enjoy, free from disease and disability. An American male born in 1990 is expected to live until 72, but can expect nine years of ill health. By 2013, life expectancy increased to 76 years, but with ten and a half years living in ill health. Since 1990, American men have gained an additional three years of healthy life and an additional four and half years of ill health. America spends a great of money keeping people alive for longer: around one quarter of America’s spending on Medicare, or healthcare for the elderly, is spent during the last six months of life alone. <http://www.economist.com/blogs/graphicdetail/2015/08/daily-chart-14>

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>

When prisons need to be more like nursing homes

KAISER HEALTH NEWS | Online – 27 August 2015 – America's prison population is rapidly graying, forcing corrections departments to confront the rising costs and challenges of health care in institutions that weren't designed to serve as nursing homes. Between 1995 and 2010 the number of inmates age 55 and up almost quadrupled, owing in part to the tough-on-crime sentencing laws of the 1980s and 1990s, according to a 2012 ACLU report. In 2013, about 10% of the nation's prison inmates – or 145,000 people – were 55 or older. By 2030, the report said, one-third of all inmates will be over 55. At the same time, it is widely accepted that prisoners age faster than the general population because they tend to arrive at prison with more health problems or develop them during incarceration. Caring for elderly inmates can often cost up to twice as much as caring for younger ones. In North Carolina, however, it costs an estimated four times as much. During the fiscal year 2006-2007 – its most recent figures – the state's corrections department spent \$33,824,060 on health care for inmates over 50, a 35% increase from just two years earlier. <http://khn.org/news/when-prisons-need-to-be-more-like-nursing-homes/>

[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 the weekly report is available on the Palliative Care Community Network website at: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>

End-of-life Medicare expenditures

“Cowboy doctors” and health costs

HARVARD MAGAZINE | Online – September-October Issue (Accessed 25 August 2015) – Who's driving up U.S. healthcare costs? A recent study by Harvard professors and colleagues revealed that the culprits may be “cowboy doctors” – physicians who provide intensive, unnecessary, and often ineffective patient care, resulting in wasteful spending costing as much as 2% of the nation's Gross Domestic Product – hundreds of billions of dollars annually.¹ The authors ... found physicians' beliefs in clinically unsupported treatment procedures can explain as much as 35% of end-of-life Medicare expenditures, and 12% of Medicare expenditures overall. Physicians treating a critically ill patient may decide either to provide intensive care beyond the indications of clinical guidelines ... or attempt to make the patient more comfortable by administering palliative care. The researchers called the former group “cowboys” and the latter “comforters,” and found that their respective concentrations in a region closely tracked end-of-life spending as a whole. The study noted that very few doctors wanted to discuss the option of palliative care with patients... <http://harvardmagazine.com/2015/08/cowboy-doctors-and-health-costs>

1. 'Physician Beliefs and Patient Preferences: A New Look at Regional Variation in Health Care Spending,' Harvard Business School (Boston, Massachusetts), Working Paper 15-090, 25 August 2015. http://www.hbs.edu/faculty/Publication%20Files/15-090_bfbc1026-8cd3-497a-845a-f57b382a348a.pdf

Related:

- NATIONAL BUREAU OF ECONOMIC RESEARCH | Working Paper 21270 – Accessed 25 August 2015 – ‘**Medical spending of the U.S. elderly.**’ Medical expenses more than double between ages 70 and 90 and they are concentrated: top 10% of all spenders are responsible for 52% of medical spending in a given year. Those currently experiencing either very low or very high medical expenses are likely to find themselves in the same position in the future. While medical expenses before death can be large, on average they constitute only a small fraction of total spending, both in the aggregate and over the life cycle. Hence, medical expenses before death do not appear to be an important driver of the high and increasing medical spending found in the U.S. <http://www.nber.org/papers/w21270>

Medicare reconsiders rule that leaves dying patients facing a stark choice

THE WASHINGTON POST | Online – 25 August 2015 – For more than 30 years, Medicare presented dying patients with a stark choice: They could continue treatments that might extend their lives or they could accept the medical and counseling services of hospice care meant to ease their way to death. They could not do both. Now, the federal government is experimenting with a change that would remove that either/or proposition. Beginning next year, people choosing to participate in a demonstration project will be able to receive Medicare hospice benefits while continuing treatment for the diseases that are killing them. If the experiment is deemed a success – by drawing more people into hospice, increasing the satisfaction of patients and their families, and reducing end-of-life costs – it probably will lead to a similar shift by private insurers and by Medicaid, the joint federal-state health insurance program for the poor. Nearly 30% of Medicare's \$600 billion annual budget is spent on treatment in the last six months of life, much of it on ex-

pensive interventions with limited benefits. Without changes, the cost of end-of-life care is likely to skyrocket as the elderly population grows. http://www.washingtonpost.com/national/health-science/medicare-reconsiders-rule-that-leaves-dying-patients-facing-a-stark-choice/2015/08/24/5245ac44-3f8d-11e5-8d45-d815146f81fa_story.html

Specialist Publications

'Right-to-try laws and individual patient "compassionate use" of experimental oncology medications: A call for improved provider-patient communication' (p.12), in *Death Studies*.

'Can faith and hospice coexist: Is the African American church the key to increased hospice utilization for African Americans?' (p.14), in *Journal of Transcultural Nursing*.

Noted in Media Watch, 27 July 2015, #420 (pp.4-5):

- *THE NEW YORK TIMES* | Online – 22 July 2015 – **'Medicare to try a blend of hospice care and treatment.'** Most older Americans close to death have to make a difficult choice: to continue with traditional medical treatment or switch to hospice care, which focuses not on a cure but on easing their remaining days. Medicare is testing a third alternative: both. A pilot program, designed to affect the care of about 150,000 Medicare patients over the next four years, will allow patients with terminal diseases to receive hospice care to manage suffering and counseling to plan for the end of life – but still see doctors and get treatments, like chemotherapy or hospitalization, intended to fight their illnesses. http://www.nytimes.com/2015/07/22/upshot/medicare-to-try-a-blend-of-hospice-care-and-treatment.html?_r=0&abt=0002&abg=1

New limits put on nursing home ads

Centers must meet state standards to advertise "memory care"

MASSACHUSETTS | *The Boston Globe* – 22 August 2015 – Massachusetts nursing homes will no longer be allowed to advertise "memory care" or similar services if they have not complied with requirements to ensure appropriate dementia care, under state rules issued last week aimed at clarifying widespread confusion. The action by the Department of Public Health follows a review by the Alzheimer's Association of Massachusetts & New Hampshire of how the state's nursing homes advertise their services. That review found nearly 60% of facilities that advertised memory, dementia, or cognitive care had not documented they had completed the training, staffing, or design changes required to be called a dementia special care facility. <https://www.bostonglobe.com/metro/2015/08/22/new-rules-tighten-dementia-ads-mass-nursing-homes/YSEEQrOgYkof7cw4LCG1YM/story.html>

Cont.

Noted in Media Watch, 15 June 2015, #414 (p.13):

- *INTERNATIONAL PSYCHOGERIATRICS* | Online – 10 June 2015 – ‘**Achieving consensus and controversy around applicability of palliative care to dementia.**’ The authors performed a Delphi study to define domains for palliative care in dementia and provide recommendations for optimal care. A panel of experts in palliative care and dementia care achieved consensus on almost all domains and recommendations. The domain concerning applicability of palliative care to dementia required revision. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9766185&fulltextType=RA&fileId=S1041610215000824>

Noted in Media Watch, 6 April 2015, #404 (p.3):

- *THE NEW YORK TIMES* | Online – 1 April 2015 – ‘**Transforming nursing home care.**’ Nursing homes have evolved from their meager beginnings as part almshouse and part boarding home into a major industry. There are now over 15,000 nursing homes in the U.S., which can house up to 1.7 million people. Nearly 70% of Americans with advanced dementia will live their final days in this setting. The problems with nursing homes are well documented. Beginning with a 1986 Institute of Medicine report.¹ http://opinionator.blogs.nytimes.com/2015/04/01/transforming-nursing-home-care/?_r=0

1. ‘Improving the Quality of Care in Nursing Homes,’ Institute of Medicine, Committee on Nursing Homes, 1986. <http://www.nap.edu/catalog/646/improving-the-quality-of-care-in-nursing-homes>

Noted in Media Watch, 30 March 2015, #403 (p.6):

- *NEW YORK MAGAZINE* | Online – 24 March 2015 – ‘**Many nursing homes fall short at palliative care.**’ In a new study, researchers attempted to see how well directors of nursing responded to questions about both personal knowledge of palliative care practices and about how their facilities handled these issues.¹ Twenty-one percent of the directors of nursing surveyed “correctly responded to only one of the knowledge items, and 43% to all items.” <http://nymag.com/scienceofus/2015/03/many-nursing-homes-fall-short-at-palliative-care.html>

1. ‘End-of-life care in nursing homes with greater versus less palliative care knowledge and practice,’ *Journal of Palliative Medicine*, 16 March 2015. This study includes 1,981 nursing homes with complete survey responses and the 58,876 residents who died in these facilities between July 2009 and June 2010. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0393?journalCode=jpm>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MINNESOTA | *The Star-Tribune* (Minneapolis) – 24 August 2015 – ‘**Final Exit Network fined \$30,000 for assisting Apple Valley woman’s suicide.**’ A national right-to-die group plans to keep operating in Minnesota despite a felony conviction and a judge’s order to pay nearly \$33,000 for assisting an Apple Valley woman’s suicide. Final Exit Network is “unrepentant” and will pay the required costs ... and continue providing information to people looking to end their lives, Robert Rivas, an attorney for the group said at Monday’s sentencing hearing in Dakota County. A jury found the corporation guilty in May of assisting Doreen Dunn’s 2007 suicide and interfering with the death scene. It was the first time the national group had been convicted of a felony for assisting a suicide. <http://www.startribune.com/final-exit-network-fined-30-000-for-assisting-apple-valley-woman-s-suicide/322700141/>



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>

International

End-of-life care in New Zealand

Palliative care review announced

NEW ZEALAND | Radio New Zealand – 27 August 2015 – The government has announced it will look at how to improve palliative care services, and what future demand could look like. 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. An estimated 17,000 adults will use palliative care services this year, and that figure is expected to grow as the population does. 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 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, palliative care educators... <http://www.scoop.co.nz/stories/PA1505/S00328/761m-more-for-palliative-care-and-hospices.htm>

N.B. New Zealand was rated 3rd (of the 40 countries surveyed) in *The Quality of Death: Ranking End-of-Life Care Across the World*, commissioned by the Lien Foundation, published by the Economist Intelligence Unit, 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Children’s Hospice Association Scotland

Families’ struggle over future young patients didn’t expect

U.K. (Scotland) | *The National* (Glasgow) – 27 August 2015 – Extra support is needed to help the families of young people with life-limiting conditions adapt to a future they were not expected to have, a report has found.¹ Thanks to medical advances, more people diagnosed with serious illnesses in childhood are surviving through adolescence and into adulthood. However, research ... found that the parents of young patients are often unprepared for their futures and can suffer trauma when asked to “let go” when they are adults. Families need training and ongoing support as their children age ... improved services for patients as they outgrow children’s hospices. The research ... focused on young people aged 15-25 found the aspirations of young adults for education, employment, in-

dependent living or relationships are often considered “unsafe or unrealistic” by family members. <http://www.thenational.scot/news/families-struggle-over-future-young-patients-didnt-expect.6846>

Specialist Publications

‘Establishing and providing pediatric palliative/hospice care in different settings or in different ways (Part 1)’ (p.17), in *ChiPPS E-Journal*.

‘The family’s experience of the child and/or teenager in palliative care: Fluctuating between hope and hopelessness in a world changed by losses’ (p.16), in *Revista Latino-Americana de Enfermagem*.

1. ‘Multiple and Multi-Dimensional Understanding the Life Transitions of Young Adults Cared for by CHAS and the Impact on their Parents, Siblings and Professionals: Final Report for Children’s Hospice Association Scotland,’ Transformative Change: Educational & Life Transitions Research Centre, University of Dundee & Sue Ryder Care Centre for the Study of Supportive, Palliative & End-of-Life Care, University of Nottingham, May 2015. http://www.chas.org.uk/assets/0001/5083/Multiple_and_Multi-Dimensional_Transitions-Executive_Summary.pdf

Cont.

Noted in Media Watch, 17 February 2014, #345 (p.12):

- *NURSING CHILDREN & YOUNG PEOPLE*, 2014;26(1):8-9. ‘**The challenges faced when leaving a children’s hospice.**’ The move into adult services can leave young people with life-shortening conditions in Scotland facing an uncertain future, as they leave the comfort of children’s services behind. Children’s Hospice Association Scotland has introduced a policy to assist young people during this transition. <http://rcnpublishing.com/doi/pdfplus/10.7748/ncyp2014.02.26.1.8.s9>

N.B. Noted in this issue of Media Watch is a selection of articles noted in past issues of the weekly report on the transition to adult services for young people living with a terminal illness.

Elder care in Australia

Aged-care response a true test of society’s caring

AUSTRALIA | *The Sydney Morning Herald* – 24 August 2015 – Elderly and frail patients as well as their loved ones can sometimes be unwilling participants of an insensitive aged-care system. There are examples of excellence, but it can seem that sadly there is not enough. Levels of care delivery in hospitals and aged-care homes vary greatly, but there is usually no way of knowing this until things go wrong. Elizabeth Rogers, an 89-year-old patient, spent three days in Prince of Wales Hospital after suffering a fall at her aged care home. She was forced out of the hospital with an eviction notice – despite protestations from her low-care home that she needed acute care. After returning to the aged-care home her condition worsened and within 48 hours staff tried to transfer her back to the hospital which refused to readmit her. Thankfully, she was accepted by another hospital. Once media descended upon the story, the hospital apologised to family members with the reassurance that the eviction notice was not “acceptable practice” and that an investigation was under way. Outrage and condemnation on social media was swift. <http://www.smh.com.au/comment/agedcare-response-a-true-test-of-societys-caring-20150824-gj6a8b.html>



Noted In Media Watch, 3 August 2015, #421 (p.6):

- AUSTRALIA | *The Australian* – 27 July 2015 – ‘**Ageing population not draining health budget, but reforms needed.**’ Modelling by the chief economist of the commonwealth Department of Health shows changes in age structure made a small contribution to the recent growth in health expenditure. <http://www.theaustralian.com.au/opinion/columnists/ageing-population-not-draining-health-budget-but-reforms-needed/story-fn7078da-1227457722398>

Sect’s death ritual clashes with Indian law

INDIA | *The New York Times* – 24 August 2015 – On a bed in a corner of a large sitting room, surrounded by a crowd of reverent visitors, the family’s 92-year-old patriarch, Manikchand Lodha, was fasting to death. It was the culmination of an act of *santhara*, a voluntary, systematic starvation ritual undertaken every year by several hundred members of the austere, ancient Jain religion. Mr. Lodha had begun the process some three years earlier, after a fall left him bedridden. First he renounced pleasures like tea and tobacco. Then things he loved, like television. He gave up medicine, even refusing an air mattress to ease his bedsores. On 10 August, he took the ancient vow and gave up food and water. When he died, the house was festooned with orange-and-white bunting. Visitors were offered bowls of sweets bathed in syrup. Mr. Lodha’s fast was significant for another reason: He took the vow on the same day that a high court judge in the state of Rajasthan declared the fast unto death to be a form of suicide, which is illegal under Indian law.¹ When the case is appealed to the Supreme Court, as expected, it will rank among a handful of instances defining when the state should interfere with religious practice – most memorably, the 1987 act that banned glorification of suttee, an outlawed ritual in which widows climbed onto their husbands’ funeral pyres and were burned to death. http://www.nytimes.com/2015/08/25/world/asia/sects-death-ritual-raises-constitutional-conflict-in-india.html?_r=0

Alzheimer's grows on global scale as world societies age

THE WASHINGTON POST | Online – 24 August 2015 – A new report on the global dimensions of Alzheimer's disease says the overall shift toward older societies on the planet means that 9.9 million people will develop dementia every year, a faster pace than previously estimated.¹ The report ... estimates that 46.8 million people worldwide have dementia. That number – which is larger than the population of Spain – will almost double every 20 years, reaching 131.5 million in 2050, the report says. The latest report noted that the prevalence of Alzheimer's cases has accelerated in East Asia and Africa compared with estimates six years ago, while the proportion of new and existing cases among populations in the Americas and Europe has fallen. The study's authors, noting that advanced age is the single highest risk factor for Alzheimer's, attribute the regional shift to the proportional growth

of older populations in developing countries. Fifty-eight percent of all people with dementia live in low- or middle-income countries, as defined by the World Bank, the report says. That number is expected to increase to 68% by 2050. <http://www.washingtonpost.com/news/local/wp/2015/08/24/alzheimers-grows-on-global-scale-as-world-societies-age/>

Extract from Alzheimer's Disease International report

Research investment for dementia should be up-scaled, proportionate to the societal cost of the disease. This research investment should be balanced between prevention, treatment, cure and palliative care.

1. 'The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trend,' Alzheimer's Disease International, August 2015. <http://www.alz.co.uk/research/world-report-2015>

N.B. Selected articles on end-of-life care for people living with dementia noted in past issues of Media Watch are listed in the issue of the weekly report of 15 June 2015, #414 (pp.13-14). Note 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,' *Palliative Medicine*, 4 July 2013. [Noted in Media Watch, 8 July 2013, #313 (p.8)] <http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract>

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

Hospital's new care plan to help ensure patients have a dignified death

U.K. (England) | *The Scunthorpe Telegraph* – 23 August 2015 – Patients who are at the end of their lives will receive the best possible care Scunthorpe hospital bosses have pledged, as they implement a new end-of-life care plan. A new role has been created at Scunthorpe General Hospital to support ward staff in ensuring dying patients' wishes are heard as part of the plan, which will be implemented by Northern Lincolnshire and Goole National Health Service (NHS) Foundation Trust. The new care plan has been developed by the Trust using guidance issued by the Government called "one chance to get it right," which sets out five key care priorities when caring for patients in their last days.¹ The plan ... replaces The Liverpool Care Pathway, which was withdrawn from use in the NHS following an independent, national review in 2013. <http://www.scunthorpetelegraph.co.uk/Hospitals-new-care-plan-8216-help-ensure/story-27637731-detail/story.html>

New palliative care data collection in England

U.K. (England) | Public Health England – 26 August 2015 – The National End-of-Life Care Intelligence Network has added information to its website about plans for a new data collection from specialist palliative care services. The dataset includes information about patient outcomes, including patient and carer views on care. It will drive improvements in individual care and address inequalities. The data will also be used to support commissioning of specialist palliative care services in England. http://www.endoflifecare-intelligence.org.uk/national_information_standard/palliative_care_dataset/

Cont.

1. 'One Chance to Get it Right: Improving People's Experience of Care in the Last Few Days and Hours of Life,' Leadership Alliance for the Care of Dying People, Department of Health, 26 June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.7)] <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

Noted in Media Watch, 17 August 2015, #423 (p.9):

- U.K. (England) | *The Daily Telegraph* – 13 August 2015 – **'Hospitals act like "conveyor belts" for dying patient.'** Nearly half of hospitals are putting dying patients at risk of harm or unnecessary suffering, the care watchdog has warned as it said those with conditions like dementia and heart disease are receiving a poorer standard of treatment. The Care Quality Commission revealed that 50 of the 105 hospitals it has inspected since November 2013 have been criticised over patient safety.¹ <http://www.telegraph.co.uk/news/nhs/11802113/Hospitals-act-like-conveyor-belts-for-dying-patients.html>

1. 'One Chance to Get it Right: One Year On,' Care Quality Commission, July 2015. Overview of progress on commitments made in the system-wide response to the review of The Liverpool Care Pathway. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/450391/One_chance_-_one_year_on_acc.pdf

Noted in Media Watch, 10 August 2015, #422 (p.6):

- U.K. (England) | *The Daily Telegraph* – 3 August 2015 – **'New National Health Service death guidelines "worse than Liverpool Care Pathway."** New guidelines on end-of-life care are worse than The Liverpool Care Pathway and could push more patients to an early grave, a leading doctor has warned.¹ <http://www.telegraph.co.uk/news/health/news/11779213/New-death-guidelines-worse-than-Liverpool-Care-Pathway.html>

1. 'Care of the Dying Adult: Draft Guideline Consultation,' National Institute for Health & Care Excellence, July 2015. (Publication December 2015) [Noted in Media Watch, 3 August 2015, #421 (p.5)] <http://www.nice.org.uk/guidance/indevelopment/GID-CGWAVE0694/consultation/care-of-the-dying-adult-draft-guideline-consultation>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GERMANY | *Deutsche Welle* (Bonn) – 27 August 2015 – **'Proposed assisted suicide controls in Germany "are unconstitutional."** Germany's plans to restrict its assisted suicide legislation have hit a new obstacle. According to a report by a study commission in the German parliament leaked to *Die Welt* newspaper, three of the draft bills currently under discussion in the German parliament are unconstitutional – on the grounds that the definitions they contain would be hard to enforce. The Bundestag is due to vote on proposals to restrict its liberal assisted suicide laws this autumn, with many members concerned about organizations that offer assisted suicide services. Germany has no legislation covering assisted suicide at all at the moment - as long as they administer the fatal drug to themselves, it is legal to provide a seriously ill person with the means to help them die. <http://www.dw.com/en/proposed-assisted-suicide-controls-in-germany-are-unconstitutional/a-18674011>
- NEW ZEALAND | *Stuff.com* – 27 August 2015 – **'Euthanasia inquiry to look at international cases and reasons for wanting to die.'** A parliamentary inquiry into euthanasia will canvas public opinion and look at international cases before making a decision on whether a law change was needed in New Zealand. Parliament's Health Select Committee has released its terms of reference for an investigation into ending a person's life... The inquiry would look at the factors that contributed to a person wanting to end their life, as well as the experiences of other countries who have adopted euthanasia laws. <http://www.stuff.co.nz/national/politics/71504391/euthanasia-inquiry-to-look-at-international-cases-and-reasons-for-wanting-to-die>

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

General practice and palliative care – The Swiss approach

BAOJ PALLIATIVE MEDICINE | Online – Accessed 27 August 2015 – This article summarises the current state of end-of-life care (EOLC) and general practice in Switzerland. It focuses on public awareness concerning EOLC, outlines political actions to strengthen EOLC, links general practice and EOLC, shows the situation in undergraduate and postgraduate training, and reimbursement and financing of end-of-life treatments. It illustrates especially, that important steps are to be made in order to improve the provision of EOLC. Further action is necessary and special attention needs to be paid to the aging workforce of Swiss GPs. <http://bioaccent.org/palliative-medicine/palliative-medicine07.pdf>

Preferences of advanced cancer patients for communication on anticancer treatment cessation and the transition to palliative care

CANCER | Online – 26 August 2015 – The majority of patients [i.e., study participants] preferred their physicians to be realistic about their likely future and wanted to be reassured that their painful symptoms would be controlled. For patients with cancer at certain sites, those with children, and those more recently diagnosed, physicians should communicate carefully and actively by providing information on life expectancy and mental preparation, sustaining hope, and behaving with empathic paternalism. Results of the descriptive analysis indicated that patients strongly preferred their physicians to listen to their distress and concerns (96%), to assure them that their painful symptoms would be controlled (97.1%), and to explain the status of their illness and the physical symptoms that would likely occur in the future (95.1%). Multiple regression analyses identified the factors associated with these preferences: telling patients to prepare mentally and informing them of their expected life expectancy were associated with cancer site; sustaining hope was associated with cancer site and children; and, empathic paternalism was associated with duration since cancer diagnosis. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.29635/abstract>

Palliative care & non-viral liver infections

Overview of palliative care and hospice services

CLINICAL LIVER DISEASE, 2015;6(2):30-32. End-stage chronic liver disease (ESLD) affects thousands of Americans. Up to 10% of eligible patients will die without undergoing transplantation, and those who await transplantation may have high symptom burden; thus, palliative care (PC) consultation for such patients to improve quality of life (and possibly quantity of life) has been proposed. PC has become increasingly utilized in other life-limiting illnesses such as cancer and advanced heart failure. Such diseases may not be imminently fatal and more so mimic chronic illness states; however, a high symptom burden from the disease or its treatment often exists. Patients with ESLD can have high morbidity and mortality and their trajectory of care may be complex, making prognostication challenging. As patients progress through life with the chronic burdens of ESLD, patients and their caregivers may have need for complex symptom management, multifaceted psychosocial evaluation, and the continual reassessment of medical options and goals of care. The authors discuss an overview what PC is and can often provide, and how this differs from traditional hospice care. <http://onlinelibrary.wiley.com/doi/10.1002/cld.486/full>

Related:

- *CLINICAL LIVER DISEASE*, 2015;6(2):33-36. 'Issues in the end-stage liver disease patient for which palliative care could be helpful.' <http://onlinelibrary.wiley.com/doi/10.1002/cld.492/full>
- *CLINICAL LIVER DISEASE*, 2015;6(2):37-40. 'Working with palliative care services.' <http://onlinelibrary.wiley.com/doi/10.1002/cld.493/full>

Right-to-try laws and individual patient “compassionate use” of experimental oncology medications: A call for improved provider-patient communication

DEATH STUDIES | Online – 27 August 2015 – The U.S. Food & Drug Administration’s Expanded Access program allows patients with life-threatening diagnoses ... to use experimental medications without participating in clinical research (colloquially, “compassionate use”). Sixteen U.S. states recently passed “right-to-try” legislation aimed at promoting Expanded Access. Acknowledging popular support, Expanded Access could undermine clinical trials that benefit public health. Moreover, existing norms in oncologic care, for example, often lead patients to pursue intense treatments near the end of life, at the expense of palliation, and improved communication about the risks and benefits of Expanded Access would more often discourage its use. <http://www.tandfonline.com/doi/full/10.1080/07481187.2015.1077356#abstract>

Noted in Media Watch, 10 August 2015, #422 (p.12):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 5 August 2015 – ‘**Questions of safety and fairness raised as right-to-try movement gains steam.**’ A patient’s right to try an investigational drug is at the core of right-to-try laws ... which the ... Goldwater Institute has championed. Yet bioethicists question whether such laws offer anything more than “the creation of false hope.”¹ Individual patients with a serious or life-threatening illness can already request investigational drugs through the FDA’s expanded access program. <http://jama.jamanetwork.com/article.aspx?articleid=2424669>
 1. ‘Should patients in need be given access to experimental drugs?’ *Expert Opinion on Pharmacotherapy*, 2015;16[9]:1275-1279. The authors discuss the impulse to rescue individual patients facing dire diseases and underscore the ethical questions that such rescue efforts raise. <http://informahealthcare.com/doi/pdf/10.1517/14656566.2015.1046837>

End-of-life care in Germany

“Good dying” – definition and current state of research

DEUTSCHE MEDIZINISCHE WOCHENSCHRIFT, 2015;140(17):1296-1301. In western countries most people die at advanced age in medical facilities. Hence, the question regarding the conditions, which should be provided by society and especially medicine, to allow terminally ill people to experience “good dying” is substantial. For this purpose, an examination of patients’ and family members’ and health care providers’ understanding of the term “good dying” is required. The attributes of “good dying” are described from the perspectives of patients, family members and health care providers, which are discussed and examined in current medical-sociological research. These attributes can be illustrated on three dimensions: 1) Quality of life at the end of life (e.g., pain relief, mental well-being); 2) Quality of dying (e.g., avoiding prolonged dying, autonomy, presence of relatives); and, 3) Quality of health care at the end of life (e.g., patient-oriented health care, positive communication between health care providers and patients, availability of guidelines). Although the attributes of “good dying” are described in detail in the existing literature, further studies have to clarify the relevance and impact of these attributes as predictors of “good dying.” <https://www.thieme-connect.de/products/ejournals/abstract/10.1055/s-0041-102676>

N.B. German language article.

Noted in Media Watch, 17 August 2015, #425 (p.14):

- *DEUTSCHES ÄRZTEBLATT INTERNATIONAL*, 2015;112(29-30):496-504. ‘**Trends over the course of a decade: A population-based study of death certificates from the years 2001 and 2011.**’ Most people in Germany die in institutions; the most common place of death is the hospital, where more than half of all deaths take place. Only 1 in 4 deaths in occur at home. There is a trend away from dying at home or in the hospital in favor of dying in a care or nursing home; death in palliative care units and hospices is becoming more common. <https://www.aerzteblatt.de/int/archive/article?id=171327>

How effective are palliative care clinicians in finding the evidence in their field?

HEALTH INFORMATION & LIBRARIES JOURNAL | Online – 21 August 2015 – Health professionals must be able to search competently for evidence to support practice. The authors sought to understand how palliative care clinicians construct searches for palliative care literature ... to quantify search efficacy in retrieving a set of relevant articles and to compare performance against a Palliative CareSearch Filter (PCSF). Included studies from palliative care systematic reviews formed a test set. Palliative care clinicians completed a search task using PubMed. Individual clinician searches were reconstructed in PubMed and combined with the test set to calculate retrieval sensitivity. PCSF performance in the test set was also determined. Many clinicians struggled to create useful searches. Twelve used a single search term, 17 narrowed the search inappropriately and 8 confused Boolean operators. The mean number of test set citations retrieved was 166, or 25% although 76% of clinicians believed they would find more than 50% of the articles. Only 8 participants (22%) achieved this. Correlations between retrieval and PubMed confidence or frequency of use were weak. Many palliative care clinicians search PubMed ineffectively. <http://onlinelibrary.wiley.com/doi/10.1111/hir.12120/abstract>

Implementation of HIV palliative care: Interprofessional education to improve patient outcomes in resource-constrained settings, 2004-2012

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2015;50(3):350-361. Palliative care (PC), introduced early in the management of chronic illness, improves patient outcomes. Early integration of a palliative approach for persons with HIV has been documented to be effective in identifying and managing patient-level concerns over the past decade in African settings. The experience of implementing PC in multiple African and other resource-constrained settings (RCSs) emphasizes the need for essential palliative competencies that can be integrated with chronic disease management for patients and their families facing life-limiting illness. This article is an historical description of how basic palliative competencies were observed to be acceptable for health workers providing outpatient HIV care and treatment during eight years of U.S. implementation of “care and support,” a term coined to represent PC for persons living with HIV in RCS. The need for team building and interprofessional education is highlighted. The model is currently being tested in one U.S. city and may represent a mechanism for expanding the palliative approach into management of chronic disease. Such competencies may play a role in the development of the patient-centered medical home, a critical component of U.S. health care reform. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00334-6/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00334-6/abstract)



Related:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 25 August 2015 – ‘**The evolution and dissemination of the Education in Palliative & End-of-Life Care Program (EPEC).**’ In its second 5 years, EPEC remains a robust platform for adaptation to new specialties and for dissemination of primary palliative care knowledge. Even with growing numbers of fellowship-trained palliative care providers, primary palliative care knowledge and skills are needed to meet the national demands for palliative care. The EPEC program has been one model of training clinicians in primary palliative care skills. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0396>

Clergy views on a good versus a poor death: Ministry to the terminally ill

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 August 2015 – A good death was characterized by wholeness and certainty and emphasized being in relationship with God. A “poor death” was characterized by separation, doubt, and isolation. Clergy [i.e., study participants] identified four primary determinants of good versus poor death: 1) Dignity; 2) Preparedness; 3) Physical suffering; and, 4) Community. They expressed appreciation for contextual factors that affect the death experience; some described a “middle death,” or one that integrates both positive and negative elements. Location of death was not viewed as a significant contributing factor. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0176>

Can faith and hospice coexist: Is the African American church the key to increased hospice utilization for African Americans?

JOURNAL OF TRANSCULTURAL NURSING | Online – 21 August 2015 – African Americans are twice as likely as Caucasian Americans to choose aggressive hospital treatment when death is imminent. This study was conducted to determine if hospices partnering with African American churches to disseminate education materials could increase utilization of hospice services by African Americans. Members of two African American churches ... participated... Lack of knowledge about hospice services and spiritual beliefs emerged as the two contributing factors for underutilization of hospice services. Findings support partnerships between hospices and African American churches to provide hospice education to the African American community. <http://tcn.sagepub.com/content/early/2015/08/20/1043659615600764.abstract>

Noted in Media Watch, 24 August 2015, #424 (p.17):

- *NARRATIVE INQUIRY IN BIOETHICS*, 2015;5(2):151-165. **'African Americans and hospice care: A narrative analysis.'** Studies suggest terminally ill African Americans' care is generally more expensive and of lower quality than of comparable non-Hispanic, white patients. Scholars argue increasing hospice enrollment among African Americans will help improve end-of-life care for this population... http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/narrative_inquiry_in_bioethics/v005/5.2_dillon.html

N.B. Additional articles on the underuse of hospice by African Americans living with a terminal illness noted in past issues of Media Watch are listed in the issue of the weekly report of 22 December 2014, #389 (p.16).

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

Life-sustaining treatment orders, location of death and co-morbid conditions in decedents with Parkinson's Disease

PARKINSONISM & RELATION DISORDERS | Online – 20 August 2015 – Decedents with Parkinson's Disease (PD) die less frequently at home than the general population. Physician Orders for Life Sustaining Treatment (POLST) forms mitigate some of this discrepancy. While not often thought to be terminal, PD and its complications are commonly recorded causes of death. [In this study] Oregon death certificates from the years 2010-2011 were analyzed. Death certificates were matched with forms in the Oregon POLST Registry. There were 1073 (1.8%) decedents with PD listed as a cause of death and 56,961 without. Three hundred and seventy three (35%) decedents with PD had a POLST form. POLST preferences were not significantly different between those with or without PD, however location of death was; hospital (13% PD vs 24% without...), home (32% vs 40%...) and care facility (52% vs 29%...). Compared to those without a POLST or those without a Comfort Measures Only (CMO) order, decedents with PD and a CMO order were less likely to die in a hospital (5.4% vs 14.7%...) and more likely to die at home (39.1% vs 29.1%...). In those with PD, dementia was the most common co-morbid condition listed on death certificates (16%). [http://www.prd-journal.com/article/S1353-8020\(15\)00360-0/abstract](http://www.prd-journal.com/article/S1353-8020(15)00360-0/abstract)

Noted in Media Watch, 30 March 2015, #403 (p.11):

- *CURRENT NEUROLOGY & NEUROSCIENCE REPORTS* | Online – 22 March 2015 – **'Palliative care for Parkinson's disease: Has the time come?'** Although Parkinson's disease (PD) is traditionally viewed as a movement disorder which affects quality of life, recent literature has revealed an increased mortality, a high burden of difficult-to-manage non-motor symptoms, high caregiver distress, and a high utilization of medical services especially in the last year of life. Current medical systems have yet to adequately respond to this mounting evidence through the adoption of palliative care practices and through the provision of palliative care services to both PD patients and to affected families <http://link.springer.com/article/10.1007/s11910-015-0542-4>

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Noted in Media Watch, 15 July 2013, #314, (p.11):

- *PALLIATIVE MEDICINE* | Online – 9 July 2013 – ‘**Palliative care for Parkinson’s disease: A summary of the evidence and future directions.**’ Despite calls for improved access to palliative care for people with Parkinson’s disease, services have been slow in developing. Obstacles include poor understanding and recognition of palliative care needs, the role for specialist palliative care services, and an agreed structure for sustainable palliative care provision. An integrated model of care, promoting collaboration between specialist palliative care services and neurological services, is discussed. <http://pmj.sagepub.com/content/early/2013/07/05/0269216313495287.abstract>

Addressing palliative sedation during expert consultation: A descriptive analysis of the practice of Dutch palliative care consultation teams

PLOS ONE | Online – 24 August 2015 – Expert consultation in the field of palliative sedation is advocated when physicians lack sufficient knowledge or expertise in the field of palliative sedation. However, mandatory consultation for palliative sedation, as argued by some, remains an ongoing debate in the recent literature. The use of expert consultation services for palliative sedation does not appear to be a common practice. This might indicate a limited need for expert consultation as a result of physicians being sufficiently skilled in this area. It might also point to an already covered need for expert consultation provided by other healthcare professionals beyond regular consultation services. Finally, there might be a neglected need for expert consultations due to physicians being unaware of their limited expertise concerning palliative sedation. <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0136309>

Noted in Media Watch, 18 May 2015, #410 (p.9):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 13 May 2015 – ‘**Language barriers to defining concepts in medicine: The case of palliative sedation.**’ Defining a concept is the process of describing its measurable properties and specifying the units of analysis to which the concept applies. Based on the classical concept theory, all concepts have a definitional structure formed by a list of features that must comprise two essential attributes, that is, necessity and sufficiency. The former entails that all denoted members share each of the features described, whereas the latter that each feature contains all parts required for a clear and unambiguous definition. Should one of these attributes is not fully satisfied, a definition can be challenged as inadequate, inappropriate, or problematic. <http://ajh.sagepub.com/content/early/2015/05/12/1049909115586186.extract>

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

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – ‘**Palliative sedation: An analysis of international guidelines and position statements.**’ Guidelines were published by 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). Variances throughout guidelines include definitions of the practice, indications for its use, continuation of life-prolonging therapies, medications used, and timing/prognosis. <http://ajh.sagepub.com/content/early/2014/05/06/1049909114533002.abstract>

It isn’t like this on TV: Revisiting CPR survival rates depicted on popular TV shows

RESUSCITATION | Online – 18 August 2015 – Public perceptions of cardiopulmonary resuscitation (CPR) can be influenced by the media. Nearly two decades ago, a study found the rates of survival following CPR were far higher in popular TV shows than actual rates.¹ In recent years, major strides toward enhanced education and communication around life-sustaining interventions have been made. This study aimed to reassess the accuracy of CPR portrayed by popular medical TV shows [i.e., ‘Grey’s Anatomy’ and ‘House’]. Additionally, the authors sought to determine whether these shows depicted discussions of

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care preferences and referenced advance directives. CPR was depicted 46 times in the 91 episodes, with a survival rate of 69.6%. Among those immediately surviving following CPR, the majority (71.9%) survived to hospital discharge and 15.6% died before discharge. Advance directive discussions only occurred for two patients, and preferences regarding code status (8.7%), intubation (6.5%) and feeding (4.3%) rarely occurred. Both popular TV shows portrayed CPR as more effective than actual rates. Overall, the shows portrayed an immediate survival rate nearly twice that of actual survival rates. Inaccurate TV portrayal of CPR survival rates may misinform viewers and influence care decisions made during serious illness and at end of life. [http://www.resuscitationjournal.com/article/S0300-9572\(15\)00373-1/abstract](http://www.resuscitationjournal.com/article/S0300-9572(15)00373-1/abstract)

1. 'Resuscitation on television: Realistic or ridiculous? A quantitative observational analysis of the portrayal of cardiopulmonary resuscitation in television medical drama,' *Resuscitation*, 2009;80(11):1275-1279. Eighty-eight episodes of television medical drama were reviewed: 26 of 'Casualty,' 25 of 'Holby City,' 23 of 'Grey's Anatomy,' and 14 of 'ER.' [Noted in Media Watch, 24 February 2014, #346 (p.6)] [http://www.resuscitationjournal.com/article/S0300-9572\(09\)00403-1/abstract](http://www.resuscitationjournal.com/article/S0300-9572(09)00403-1/abstract)

Noted in Media Watch, 18 March 2013, #297 (p.13, under 'Worth Repeating'):

- *NEW ENGLAND JOURNAL OF MEDICINE*, 1996;334(24):1578-1582. 'Cardiopulmonary resuscitation on television: Miracles and misinformation,' The survival rates are significantly higher than the most optimistic survival rates in the medical literature, and the portrayal of CPR on television may lead the viewing public to have an unrealistic impression of CPR and its chances for success. <http://www.nejm.org/doi/full/10.1056/NEJM199606133342406#t=articleTop>

Related:

- *PULSE* (U.K.) | Online – 28 August 2015 – “**Do not resuscitate” form is not fit-for-purpose, say GPs.**’ A form introduced across Wales to record whether patients with life-limiting illness or severe frailty wish to be resuscitated is “not fit for purpose,” National Health Service (NHS) Wales has been told by GPs. The GPs argue that the form is old-fashioned and unwieldy because it requires carbonated paper and has six copies, and it is not clear where all of them are supposed to be sent. NHS Wales introduced the standardised “do not attempt cardio pulmonary resuscitation” form across both primary and secondary care to provide a “consistent and integrated approach” so that patients and families feel involved in decisions about resuscitation. It has sections summarising why CPR might be inappropriate, whether the patient has capacity to make decisions about CPR, and whether carers/families have been involved in discussions. <http://www.pulsetoday.co.uk/news/clinical-news/do-not-resuscitate-form-is-not-fit-for-purpose-say-gps/20010834.article#.VeCzbc9RGos>

The family's experience of the child and/or teenager in palliative care: Fluctuating between hope and hopelessness in a world changed by losses

REVISTA LATINO-AMERICANA DE ENFERMAGEM, 2015;23(3):560-567. The study has shown that recognizing palliative care is an uphill battle for the family, since it puts them in uncertainty and regarding the future and the possibility of death. The narrative of the family, recognizing the benefits of palliative care does not mean accepting death because this is a reality that they will never be accepted, but it is their way of dealing with loss along the way and keep their hope and perseverance, to focus on the management of child care. This means that the family experiences the sense of loss over the journey of the disease and not just after their child's death, what needs to be recognized by the professional who is attending them. Thus, this study in conjunction with [the published] literature, demonstrates that the family can find a new way to continue living despite the loss in which the process of experiencing the palliative care and the consequent death of the child occurs with less conflict. But this is only possible when the context admits the recognition of suffering, doubt, offers appropriate information, and allows a space where the family can share ideas, feelings and facilitates access to social support. These conditions need to be respected, when working with the family, so that it allows its members to give meaning and construct a new reality regarding the experiences and interactions where they can support each other and seek to decrease the suffering existing in these experiences. This caring of the family, which should be

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carried out gradually during the path of palliative care, will reflect in their confrontation of later formulations regarding the issues of grief and death and how they will lead their life after the death of their loved one. <http://www.scielo.br/pdf/rlae/v23n3/0104-1169-rlae-23-03-00560.pdf>

N.B. Original Portuguese-language article: 'La experiencia del familiar de niños y/o adolescentes en los cuidados paliativos: fluctuante entre la esperanza y la desesperanza en un mundo transformado por las pérdidas.' http://www.scielo.br/pdf/rlae/v23n3/pt_0104-1169-rlae-23-03-00560.pdf

Related:

- *CHIPPS E-JOURNAL* (Children's Project on Palliative/Hospice Services) | Online – Accessed 27 August 2015 – '**Establishing and providing pediatric palliative/hospice care in different settings or in different ways (Part 1).**' This issue explores selected issues in establishing and providing pediatric palliative/hospice care in different settings or in different ways. The articles offer suggestions for and examples of engaging in the important work of providing pediatric palliative/hospice care. http://www.nhpco.org/sites/default/files/public/ChiPPS/ChiPPS_ejournal_Issue-40.pdf
- *JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY* | Online – 25 August 2015 – '**Legacy making through illness blogs: Online spaces for young adults approaching the end-of-life.**' Little is known about young adults with cancer at the end-of-life, but life review and legacy making may be important modalities to process the emotions associated with anticipatory grief. The study analyzed the illness blogs of five young women ... at the end of life... The women had varying experiences before their death, but uniform posthumous occurrences with the use of the blog for a space of grief for loved ones. The use of online blogs among adolescents and young adults with advanced cancer is an area of needed further study. <http://online.liebertpub.com/doi/abs/10.1089/jayao.2015.0003>

Media Watch: Editorial Practice

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

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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.

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/publications/newsletter/2015/08/media-watch/>

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

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

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

Asia

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

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

Australia

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

Canada

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

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

Europe

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

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

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

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