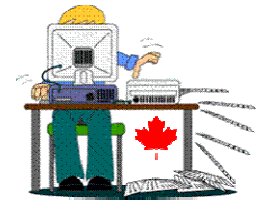


Media Watch...

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

The Illness experience: Scroll down to [Specialist Publications](#) and 'The diverse impact of advance care planning: A long-term follow-up study on patients' and relatives' experiences' (p.8), in *BMJ Supportive & Palliative Care*.

Canada

Statistics Canada report

Preparing for the “grey tsunami”

THE TORONTO STAR (Ontario) | Online – 30 September 2015 – Official confirmation of a long-predicted tipping point came this week with Statistics Canada confirming this country's seniors now outnumber its children.¹ The announcement managed the tricky feat of being both expected and a revelation. According to one headline, the country is “fading to grey” – but it's been heading that way for decades. What's different now is Canada has certifiably joined the family of industrialized nations that have more grandparents than grandkids. As of Canada Day [1 July of] this year, 16.1% of us were 65 or older. At the same time, those under the age of 15 made up 16% of the population. By itself, this is no cause for panic. But time – and demographics – don't stand still. Statistics Canada projects by 2024 (nine years away) more than one in five Canadians will be a senior citizen. This trend carries massive implications, especially for Canada's already over-stretched health care system. It's especially worrisome that the growing needs of an aging population are being so poorly satisfied now. More than 460,000 Canadians reported their need for home care was going entirely unmet, according to a study last fall.² That's almost half a million aged and ailing people going utterly without. Another 330,000 said they were receiving some assistance, but not as much as they needed. The research ... specifically excluded people in institutions or long-term care. <http://www.thestar.com/opinion/editorials/2015/09/30/preparing-for-the-grey-tsunami-editorial.html>

1. 'Annual Demographic Estimates: Canada, Provinces & Territories,' Statistics Canada, September 2015. http://www.statcan.gc.ca/pub/91-215-x/91-215-x2015000-eng.htm?WT.mc_id=twf
2. 'Study: Canadians with unmet home care needs, 2012,' Statistics Canada, September 2014. [Noted in Media Watch, 15 September 2014, #375 (p.2)] <http://www.statcan.gc.ca/daily-quotidien/140909/dq140909a-eng.htm?HPA>

Cont.

Noted in Media Watch, 5 September 2011, #200 (p.1):

- CANADA (British Columbia) | CBC News – 29 August 2011 – ‘**Cost of aging population on health care “overblown.”**’ Fears Canada’s aging population could lead to soaring health-care costs may be greatly exaggerated, say researchers, who suggest that the predicted “grey tsunami” may turn out to be more like a “grey glacier.” Two studies by health economists at the University of British Columbia say other factors are driving up health-care costs – primarily the growing use of specialists, increasing diagnostic tests for the elderly, and the higher consumption of ever more costly drugs. <http://www.cbc.ca/news/health/story/2011/08/29/grey-tsunami-aging-population.html>

Unpaid caregivers say they are abandoned by family and friends



NOVA SCOTIA | CBC News – 29 September 2015 – Two and a half years ago, when Blanche Robinson took on the role of unpaid caregiver to her 83-year-old father, she says the home care staff assigned to aid with his care were a great support. The problem, she says, was her own family. They refused to step up ... as she took on the physically and emotionally taxing role of caring for her father and watch him decline with dementia, diabetes and mobility problems. Care-givers Nova Scotia, an organization designed to help unpaid caregivers, says stress and social isolation are two of the top negative health outcomes reported by family and friend caregivers. <http://www.cbc.ca/news/canada/nova-scotia/unpaid-caregivers-say-they-are-abandoned-by-family-and-friends-1.3241427>

Noted in Media Watch, 7 September 2015, #426 (p.18, under ‘Worth Repeating’):

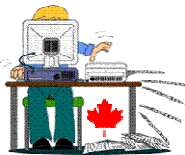
- *CANADIAN JOURNAL OF PSYCHIATRY*, 2004;49(6):359-365. ‘**Palliative care for families: Remembering the hidden patients.**’ The illness experience profoundly affects family members’ psychological and physical health; recognition of this has coined the term “hidden patients.” The authors discuss how to define the family, emphasizing a systems approach to family care. They describe the impact of the illness on the family in terms of family members’ health, family communication issues, psychological issues, needs for information, physical care demands, and family costs of caring. <https://www1.cpaapc.org/Publications/Archives/CJP/2004/june/kristjanson.pdf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE TORONTO STAR* | Online – 28 September 2015 – ‘**Poll suggests growing tolerance on key social issues.**’ Has Canada become more tolerant on hot-button issues? That’s what the results of a new ... survey on key social issues seem to suggest.¹ The poll of 1,557 randomly selected adults found that a majority believe assisted suicide should be made legal... In response to the question “Should assisted suicide be legal or not?” 67% said yes, 23% said no, and 11% said that they don’t know. <http://www.thestar.com/news/canada/2015/09/28/poll-suggests-growing-tolerance-on-key-social-issues.html>

1. The Forum Poll – Overview & Poll Data: <http://poll.forumresearch.com/post/1389/legal-prostitution-assisted-suicide-marijuana-all-win>



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.

Poll finds overwhelming support for Medicare paying for end-of-life talks

KAISER HEALTH NEWS | Online – 30 September 2015 – Eight of 10 people surveyed by the Kaiser Family Foundation supported the government or insurers paying for planning discussions about the type of care patients preferred in the waning days or weeks of their lives. These discussions can include whether people would want to be kept alive by artificial means even if they had no chance of regaining consciousness or autonomy and whether they would want their organs to be donated. These preferences can be incorporated into advance directives, or living wills, which are used if someone can no longer communicate. The notion of helping patients prepare for death has support among many doctors, who sometimes see terminal patients suffer from futile efforts to keep them alive. Last year, the Institute of Medicine issued a report that encouraged end-of-life discussions beginning as early as 16 years old.¹ The Kaiser poll found these talks remain infrequent. Overall, only 17% of those surveyed said they had had such discussions with their doctor or another health care professional, even though 89% believe doctors should engage in such counseling. A third of respondents said they had talked to doctors about another family member's wishes for how they would want to be cared for at their end. <http://khn.org/news/poll-finds-overwhelming-support-for-medicare-paying-for-end-of-life-talks/>

Where clergy need to tread: Helping make end-of-life medical choices

NEW YORK STATE | *The New York Times* – 29 September 2015 – What are the most difficult and painful questions rabbis, priests, pastors or imams face at the bedside of a dying member? Helping make realistic and sensible medical decisions is becoming the single most important aspect in a clergyperson's life. The New State Task Force on Life and the Law is a 25-member group of clergy, physicians, nurses, lawyers, ethicists, social workers and hospital administrators created 30 years ago by then-Governor Mario Cuomo. He wanted the task force to draft pioneering legislation focused on patients' rights, including do-not-resuscitate orders, health care proxies (medical powers of attorney), laws relating to surrogate parenting, medically assisted suicides, the legal and medical definition of death, and a host of other bioethical issues. https://www.washingtonpost.com/national/religion/where-clergy-need-to-tread-helping-make-end-of-life-medical-choices-commentary/2015/09/29/dafc2570-66d6-11e5-bdb6-6861f4521205_story.html

Specialist Publications

'The growth of palliative care in U.S. hospitals: A status report' (p.14), in *Journal of Palliative Medicine*.

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>

Related:

- *THE WALL STREET JOURNAL* | Online – 27 September 2015 – '**How doctors can approach end-of-life conversations.**' In 2016, after years of controversy, Medicare plans to begin reimbursing doctors for having discussions with patients about what type of medical care they want and don't want near the end of their lives. Private insurers are likely to follow, some experts say, meaning voluntary end-of-life counseling could soon become a part of standard medical care. For many in the medical community, it's a much-needed change. Most researchers and physicians agree that too many people in the U.S. receive treatments they never would have wanted or that don't align with their values as they near death. Indeed, although most people if given a choice would prefer to spend their final days at home, surrounded by loved ones, about 70% of people die in hospitals, nursing homes and long-term care facilities... <http://www.wsj.com/articles/how-doctors-can-approach-end-of-life-conversations-1443407564>

Hospital workers find solace in pausing after a death

KAISER HEALTH NEWS | Online – 28 September 2015 – For trauma workers like Jonathan Bartels, a nurse who has worked in emergency care and palliative care, witnessing death over and over again takes a toll. Over time, they can become numb or burned out. But about two years ago, after Bartels and his team at the University of Virginia Medical Center ... tried and failed to resuscitate a patient, something happened. “We had worked on this patient for hours and the chaplain came in and kind of stopped everyone from leaving the room, and I’m like, ‘Wow, that’s really bold,’” he said. “She said, ‘I’m just going to pray over this patient and then you all can leave.’ And I watched it and I felt – it was the act of stopping people – really inspired me.” While the prayer wasn’t totally comfortable to him because Bartels, like many at the hospital, is from a different religious tradition, the pause felt right. “So the next time we worked on another person who didn’t make it, I decided to be bold and stop people from leaving,” he said. The team did it – they stopped, just for a minute. The idea began to spread throughout the hospital, particularly to emergency department workers. The Pause, as it has become known, also is being taught as part of the curriculum at University of Virginia nursing school. <http://khn.org/news/hospital-workers-find-solace-in-pausing-after-a-death/>

Millions of Americans are getting lost in translation during hospital visits



SMITHSONIAN | Online – 28 September 2015 – Rampant miscommunication compromises patient safety and quality of care while widening existing health disparities. Some technological solutions are on the rise, from videoconferencing sessions with interpreters to Smartphone applications that act as digital translators, but these innovations have a ways to go before they can stand in for medically trained in-person aid. Unbeknownst to many patients and physicians, individuals with limited English proficiency have been guaranteed language services under federal law for decades. Because virtually all healthcare providers accept Medicare, Medicaid or some other form of federal funding, the rulings imply that providers cannot discriminate based on language and must supply an interpreter for limited English proficiency patients. Only 13 states and Washington, DC have elected to specifically reimburse the costs of medical interpreters through Medicaid. The remaining states – including those with the largest non-English speaking populations, such as California and Florida – argue that the costs of language services are factored into existing reimbursement rates. As a result, providers who are responsible for a higher percentage of the limited English proficiency population are forced to bear the costs of supplying interpreters on their own, which cuts into operating costs and puts the communities they serve at a disadvantage. <http://www.smithsonianmag.com/innovation/millions-americans-are-getting-lost-translation-during-hospital-visits-180956760/?no-ist>

Noted in Media Watch, 14 September 2015, #427 (pp.6-7):

- *BMC HEALTH SERVICES RESEARCH* | Online – 10 September 2015 – ‘**Overcoming language barriers in healthcare: A protocol for investigating safe and effective communication when patients or clinicians use a second language.**’ The rising number of migrant patients and foreign-trained staff means that communication errors between a healthcare practitioner and patient when one or both are speaking a second language are increasingly likely. This protocol outlines a hospital-based study examining interactions between healthcare practitioners and their patients who either share or do not share a first language. <http://www.biomedcentral.com/content/pdf/s12913-015-1024-8.pdf>

[Media Watch: Online](#)

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.19.

How house calls can cut medical costs

THE WALL STREET JOURNAL | Online – 27 September 2015 – Across the U.S., home-based primary-care practices are sending doctors, nurses and other clinicians on regular house calls to older, infirm patients. The goal is to prevent costly hospital stays and admissions to long-term-care facilities, while improving the quality of care, especially for the sickest 5% of Medicare beneficiaries, who account for 50% of the federal program's costs. Unlike traditional visiting-nurse services, which step in for a few weeks after a patient is discharged from the hospital, the home-based primary-care model calls for continuing appointments. The patients, often frail and homebound, typically are struggling to manage multiple serious illnesses, such as dementia, congestive heart failure, stroke and cancer. Evidence has mounted that primary care at home, though not inexpensive to provide, can be more economical than a constant cycle of

emergency-room visits and hospital stays. According to a study published last year¹ ... Medicare costs for patients in a home-based primary-care program in Washington DC, were 17% lower than those for a control group, averaging \$8,477 less per beneficiary over two years. Another study in the same journal, of Veterans Affairs home-based care, showed it not only reduced costs but also led to higher patient satisfaction.² <http://www.wsj.com/articles/how-house-calls-can-cut-medical-costs-1443407612>

Specialist Publications

'Rural emergency nurses' end-of-life care obstacle experiences: Stories from the last frontier' (p.13), in *Journal of Emergency Nursing*.

1. 'Effects of home-based primary care on Medicare costs...', *Journal of the American Geriatrics Society*, 2014;62(10):1825-1831. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.12974/abstract>
2. 'Better access, quality, and cost for clinically complex veterans with home-based primary care,' *Journal of the American Geriatrics Society*, 2014;62(10):1954-1961. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.13030/abstract>

Noted in Media Watch, 21 April 2014, #354 (p.2):

- *THE NEW YORK TIMES* | Online – 19 April 2014 – **'House calls are making a comeback.'** A relic from the medical past ... is returning to favor as part of some hospitals' palliative care programs, which are sending teams of physicians, nurses, social workers, chaplains and other workers to patients' homes after they are discharged. The goal is twofold: to provide better treatment and to cut costs. <http://www.nytimes.com/2014/04/20/business/house-calls-are-making-a-comeback.html?ref=health&r=0>

Related:

- MICHIGAN | Public News Service – 30 September 2015 – **'Family caregiver bill could ease burden for millions.'** More than 2 million Michiganders currently balance the demands of their own lives and jobs with caring for loved ones, and supporters of a bill making its way through the Legislature say it would help ease their burden while reducing costs all around. A Senate committee heard testimony on the CARE Act, which would require hospitals to record the name of a family caregiver when the loved one is admitted, notify that caregiver if the patient is transferred, and provide the caregiver with some training upon the loved one's discharge. <http://www.publicnewsservice.org/2015-09-30/senior-issues/family-caregiver-bill-could-ease-burden-for-millions/a48356-1>

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>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- TENNESSEE | *The Tennessean* (Nashville) – 29 September 2015 – ‘**Judge rules against legalizing assisted suicide in Tennessee.**’ A former Democratic gubernatorial candidate who is terminally ill cannot die by assisted suicide, a judge ruled saying doctors engaging in such a practice are committing “criminal conduct.” John Jay Hooker has terminal cancer and has doctors who have expressed a willingness to prescribe him a lethal dosage of painkillers. State law allows a person to refuse end-of-life care, but so-called aid-in-dying or assisted suicide is illegal in Tennessee. Doctors in Oregon, Washington, Vermont and Montana can prescribe life-ending drugs, and California lawmakers passed legislation earlier this month [yet to be signed into law] that would allow terminally ill patients to legally end their lives. <http://www.tennessean.com/story/news/local/davidson%20/2015/09/29/judge-rules-against-tn-assisted-suicide/73048034/>

International

Four opportunities missed to diagnose prisoner with inoperable brain tumour, prisoner ombudsman finds

U.K. (Northern Ireland) | *The Belfast Telegraph* – 29 September 2015 – An investigation was carried out into the death of released prisoner Mr. H in September 2014. He had been released from Maghaberry Prison at the end of July due to an inoperable brain tumour. The clinical reviewer recognised that some of Mr. H’s care was “very good.” However, four opportunities to diagnose his tumour were missed and care plans were not initiated when he became dehydrated and malnourished. The report said that although “earlier diagnosis would not have changed the final outcome, opportunities for an extended life expectancy and a reduction in his distress through earlier palliative care could have been provided.” <http://www.belfasttelegraph.co.uk/news/northern-ireland/four-opportunities-missed-to-diagnose-prisoner-with-inoperable-brain-tumour-prisoner-ombudsman-finds-31567396.html>

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>

End-of-life care in England

Half of all services now failing as U.K. care sector crisis deepens

U.K. (England) | *The Guardian* – 26 September 2015 – Nearly half of social care services visited by inspectors in the past year were found to be failing the frail and vulnerable, in what relatives and experts say is a symptom of the growing financial crisis in the sector. An update given to the board of the Care Quality Commission last week showed that 41% of community-based adult social care services, hospice services and residential social care services inspected since last October were inadequate or required improvement. Of the 8,170 services examined, less than 1% (38) were outstanding and 58% (4,381) were good, according to the chief executive’s report. Since 2010, cuts in council-funded adult social care have totalled £4.6 billion, or 31% in real terms of net budgets. These budgets

will be cut by a further £500 million this year. <http://www.theguardian.com/society/2015/sep/26/nearly-half-social-care-services-failing-uk-elderly-disabled-welfare>

N.B. Care Quality Commission website: <http://www.cqc.org.uk/>

Specialist Publications

‘**The importance of identifying preferred place of death**’ (p.9), in *BMJ Supportive & Palliative Care*.

‘**Nine in 10 nurses can’t deliver “right level” of palliative care**’ (p.15), in *Nursing in Practice*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SPAIN | *el País* (Madrid) – 2 October 2015 – **‘Parents of terminally ill Galician child fight to take her off life support.’** Andrea, a 12-year-old girl with a degenerative, irreversible disease, will likely remain at Hospital Clínico in Santiago de Compostela despite her parents’ plea to take her off life support. The pediatrics department at the Galician hospital is rejecting a non-binding report by the regional government’s bioethics committee recommending that Andrea be disconnected from the machines and offered palliative care. While the 12-year-old’s parents insist that their child is suffering, Clínico doctors say she feels no pain. Andrea’s parents have now turned to the courts. A Santiago judge on Friday requested four expert reports, including one from the chief forensic doctor at the Galicia Legal Medicine Institute (Imelga), to know whether Andrea’s life support was “unnecessarily prolonging the child’s agony.” The judge has also requested a report from the head of the pediatrics department at the hospital, with an explanation of why he believes that Andrea “feels no disproportionate suffering.” This department has rejected the parents’ plea for a dignified death for their child. Meanwhile, Galician health chief Rocío Mosquera supports the doctors’ stand and has called the parents’ petition “active euthanasia.” http://elpais.com/elpais/2015/10/01/inenglish/1443707414_872653.html
- IRELAND | *The Irish Examiner* (Blackpool, Cork) – 28 September 2015 – **‘Farming Poll 2015: Half of farmers support assisted suicide.’** *The Irish Examiner*/ICMSA poll found a majority (53%) agreed assisted suicide should be permitted in certain circumstances, with 22% strongly in favour. However, 25% of respondents were strongly opposed to such a move. Support for a change in the law was strongest among the 35 to 44 years age group, while the lowest level of support was among those aged 65 and over. Support for such a measure was also lower among regular Mass-goers. Among those who said they attended Mass every week, 19% said they were strongly in favour and 23% said they were slightly in favour, but 40% of respondents said they strongly disagreed with any changes to the law to allow for assisted suicide. <http://www.irishexaminer.com/farming/news/farming-poll-2015-half-of-farmers-support-assisted-suicide-356231.html>

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

Right-to-try laws: Hope, hype, and unintended consequences...

ANNALS OF INTERNAL MEDICINE | Online – 29 September 2015 – Some terminally ill patients want to use drugs and devices that are too early in their development to be approved by the U.S. Food & Drug Administration. As a result, some states have recently passed “right-to-try” laws that authorize patients to request these treatments from the manufacturer. Several other states are considering similar legislation. What is uncertain is whether these laws provide the benefits they promise. Most right-to-try laws do not set qualifications for either the health care provider making attestation of terminal illness or the physician recommending experimental treatment. Worse, the door is left open for the unscrupulous or inept to prey on desperately ill patients and their families. Nothing is in place to stop the creation of research “mills” in which interventions with no scientific evidence are prompted as possible cures, which has happened in the field of stem cell-based treatments. Further, the laws absolve companies and physicians from legal liability should be the experimental product cause harm. <http://annals.org/article.aspx?articleid=2443961>

Selected articles, reports, etc., on right-to-try laws

Noted in Media Watch, 7 September 2015, #426 (p.3):

- U.S. (California) | *The Los Angeles Times* – 1 September 2015 – **‘Senate approves ‘Right-to-Try Act’ for seriously ill.’** The state Senate approved a bill that would allow makers of experimental drugs to make them available to Californians with life-threatening diseases. The measure, which goes back to the Assembly for action on amendments, applies to drugs, devices and biological products that have undergone clinical trials, but have not yet been approved for general public use by the U.S. Department of Agriculture [sic]. <http://www.latimes.com/local/political/la-me-pc-senate-approves-right-to-try-legislation-for-seriously-ill-20150901-story.html>

Cont.

Noted in Media Watch, 31 August 2015, #425 (p.12):

- *DEATH STUDIES* | Online – 27 August 2015 – ‘**Right-to-try laws and individual patient “compassionate use” of experimental oncology medications...**’ Sixteen U.S. states recently passed “right-to-try” legislation aimed at promoting the U.S. Food & Drug Administration’s Expanded Access Program which could undermine clinical trials that benefit public health. Moreover, existing norms in oncologic care often lead patients to pursue intense treatments near the end of life, at the expense of palliation. <http://www.tandfonline.com/doi/full/10.1080/07481187.2015.1077356#abstract>

End-of-life care in a psychiatric hospital

BJPYSCH BULLETIN | Online – 28 September 2015 – Since the Liverpool Care Pathway has been withdrawn in the U.K., clinicians supporting the palliative needs of patients have faced further challenges, particularly for patients with dementia who are unable to go to a hospice owing to challenging behaviours. It is becoming more important for different services to provide long-term palliative care for patients with dementia. Mental health trusts should construct end-of-life care policies and train staff members accordingly. Through collaborative working, dying patients may be kept where they are best suited. The authors present the case study of a patient who received end-of-life care at a psychiatric hospital in the U.K. <http://pb.rcpsych.org/content/early/2015/09/23/pb.bp.114.049833.abstract>

Noted in Media Watch, 11 May 2015, #409 (p.6):

- *BRITISH JOURNAL OF PSYCHIATRY BULLETIN*, 2015;1-3. ‘**End-of-life care in psychiatry: “One chance to get it right.”**’ The Leadership Alliance for the Care of Dying People published ‘One Chance to Get it Right.’¹ This nationally accepted guidance replaces previous end-of-life care pathways and outlines how dying patients should be managed irrespective of setting. Increasingly, patients with mental health problems are entering their final days of life within psychiatric in-patient or acute hospital settings, and psychiatrists need to be aware of the new guidance and ready to implement it within psychiatric practice. <http://pb.rcpsych.org/content/pbrpsych/early/2015/04/26/pb.bp.114.049684.full.pdf>

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, 2014. [Noted in Media Watch, 30 June 2014, #364 (p.7)] <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

The diverse impact of advance care planning: A long-term follow-up study on patients’ and relatives’ experiences

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 30 September 2015 – The study reveals great diversity in patient and relative experiences of advance care planning (ACP). It challenges previous research, which mainly emphasises ACP as a valuable tool to optimise end-of-life care (EOLC). This study stresses the importance of awareness of the highly individual nature of preferences and needs of patients and relatives regarding information, involvement and communication about EOLC. Some patients and relatives felt “relieved,” “more secure,” and more in control due to ACP. To some, ACP had led to open communication rather than “beating around the bush,” and to spending more quality time together. However, others perceived ACP as irrelevant. Some stated that the patient’s wishes had not been met regardless of ACP. Others felt that end-of-life (EOL) questions cannot be realistically considered until “you’re in the middle of it,” because many factors are involved. In one case, ACP led to a patient-relative conflict, resulting in EOL issues being “tucked away.” <http://spcare.bmj.com/content/early/2015/09/30/bmjspcare-2015-000886.abstract>

Related:

- *PRIMARY HEALTH CARE*, 2015;25(8):18-23. ‘**End-of-life care planning in community hospitals.**’ The implementation of a palliative and supportive care plan across community hospitals in the Grampian region of ... Scotland provided an opportunity to confirm the important role staff play in palliative and end-of-life care. Reviews were collated on 130 deaths (77% of all the deaths during the project). These revealed examples of good practice, as well as the challenges faced by staff working in community hospitals. <http://journals.rcni.com/doi/abs/10.7748/phc.25.8.18.e993>

The importance of identifying preferred place of death

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 25 September 2015 – All deaths of patients known to the specialist palliative care service over a 5-year period were examined through service evaluation to compare the actual place of death with the preferred place of death previously identified by the patient. Triggers for admission were established when the patients did not achieve this preference. Between 2009 and 2013, 73% of patients [in a Cardiff hospital] who expressed a choice about their preferred place of death and 69.3% who wanted to die at home were able to achieve their preferences. During the course of their illness, 9.5% of patients changed their preference for place of death. 30% of patients either refused to discuss or no preference was elicited for place of death. Direct enquiry and identification of preferences for end-of-life care is associated with patients achieving their preference for place of death. Patients whose preferred place of death was unknown were more likely to be admitted to hospital for end-of-life care. <http://spcare.bmj.com/content/early/2015/09/25/bmjspcare-2015-000878.abstract>

Related:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 September 2015 – ‘**Preferred and actual location of death: What factors enable a preferred home death?**’ Among all who voiced a preference, 52% died in their preferred location. Factors contributing independently to achievement of a preferred home death were 1) Emotional needs being met; 2) Nursing and family physician home visits; 3) Palliative care program involvement; and, 4) Being at home for the majority of the last month. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0177>
- *SCANDINAVIAN JOURNAL OF CARING SCIENCES* | Online – 22 September 2015 – ‘**Factors associated with preference for dying at home among terminally ill patients with cancer.**’ The study showed socio-economic factors such as gender, level of income, and size of community were associated with preference for dying at home. This study advocates a more nuanced picture of the subject. <http://onlinelibrary.wiley.com/doi/10.1111/scs.12265/abstract?userIsAuthenticated=false&deniedAccessCustomisedMessage=>

Selected articles, reports, etc., on preferred place of death

Noted in Media Watch, 25 May 2015, #411 (p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 19 May 2015 – ‘**The preferences and perspectives of family caregivers towards place of care for their relatives at the end of life: A systematic review and thematic synthesis of the qualitative evidence.**’ A greater understanding would identify how best to support families at the end of life, ensuring more patients are cared for in their preferred location. <http://spcare.bmj.com/content/early/2015/05/19/bmjspcare-2014-000794.abstract>

Noted in Media Watch, 13 April 2015, #405 (p.8):

- *END OF LIFE JOURNAL* | Online – 1 March 2015 – ‘**Preferred place of death: Determining factors and the role of advance care planning.**’ The implementation of advance care planning discussions has been associated with an increased likelihood of terminally ill patients dying in their preferred place. <http://eolj.bmj.com/content/5/1/e900004.abstract>

Noted in Media Watch, 22 September 2014, #376 (p.12):

- *JOURNAL OF PALLIATIVE CARE*, 2014;30(3):141-150. ‘**Factors associated with fulfilling the preference for dying at home among cancer patients: The role of general practitioners.**’ GPs’ provision of palliative care is related to the fulfillment of cancer patients’ preferences for home death across all four countries studied [i.e., Belgium, The Netherlands, Italy and Spain]. This is an important finding as GPs are expected to play an increasing role in ensuring access to palliative care for all patients. <http://nvl002.nivel.nl/postprint/PPpp5557.pdf>

N.B. Additional articles on this issue are listed in Media Watch, 3 June 2013, #308 (pp.12-13).

Reality of evidence-based practice in palliative care

CANCER BIOLOGY & MEDICINE, 2015;12(3):1930200. There has been a paradigm shift in medicine away from tradition, anecdote and theoretical reasoning from the basic sciences towards evidence-based medicine (EBM). In palliative care, however, statistically significant benefits may be marginal and may not be related to clinical meaningfulness. The typical treatment vs. *placebo* comparison necessitated by “gold standard” randomised controlled trials is not necessarily applicable. The complex multi-morbidity of end-of-life care involves considerations of the patient’s physical, psychological, social and spiritual needs. In addition, the field of palliative care covers a heterogeneous group of chronic and incurable diseases no longer limited to cancer. Adequate sample sizes can be difficult to achieve, reducing the power of studies and high attrition rates can result in inadequate follow up periods. This review uses examples of the management of cancer-related fatigue and death rattle ... to demonstrate the current state of EBM in palliative care. The future of EBM in palliative care needs to be as diverse as the patients who ultimately derive benefit. <http://www.cancerbiomed.org/index.php/cocr/article/view/871>

Related:

- *BMC PALLIATIVE CARE* | Online – 29 September 2015 – ‘Strategies to implement evidence into practice to improve palliative care: Recommendations of a nominal group approach with expert opinion leaders.’ Research projects generate a growing amount of new knowledge. Often this new knowledge is not implemented in daily practice, particularly in an environment as complex as palliative care. Timely efforts should be made to ensure that the future application of scientific findings is integrated into the research itself, to prevent wasting resources and as an endpoint for better healthcare for patients. The recommendations reported here may be of particular use in promoting quality improvement activities in palliative care. Important stakeholders, such as scientific and professional organizations and leaders on the level where the actual implementation takes place, can perform a key role in the wider implementation of new evidence. <http://www.biomedcentral.com/1472-684X/14/47>

Expressions of loss and separation

Parental divorce and parental death – An integrative systematic review of children’s double bereavement

CLINICAL NURSING STUDIES, 2015;3(4):103-111. The lack of studies on double bereavement may perhaps reflect the fact that bereavement research and divorce research traditionally have been two separate research fields without much interchange. This is notable since both focus on profound losses within family relationships. A corresponding separation also seems to exist when it comes to support measures aiming at individuals experiencing any of these losses. Thus, future research on double bereavement as well as development of any support measures aiming at doubly bereaved children and adolescents may imply more cooperation between experts of bereavement and divorce, respectively. This way the research and clinical practice focusing on double bereavement could contribute to dismantle the inapt barriers between the fields of bereavement and divorce, and therefore represent a valuable bridge between these fields. <http://www.sciedupress.com/journal/index.php/cns/article/viewFile/7021/4763>

Assisting the bereaved: A systematic review of the evidence for grief counselling

PALLIATIVE MEDICINE | Online – 28 September 2015 – Grief counselling interventions require a strong rationale for design, and a systematic approach to development and evaluation. Descriptive research efforts should inform this process, focusing on homogeneity in sample, identification of risk factors for complicated grief, and the impact of extraneous factors on intervention effects. Interventions should include comparisons to usual care, as well as replication to confirm positive findings. 126 data-based papers – 47 descriptive, 3 measurement and 76 grief counselling intervention studies – were included. 59% of intervention studies met Effective Practice & Organisation of Care design criteria. Overall, study quality was poor, with the majority of interventions showing a risk of bias in several key areas. The three studies that met all criteria showed mixed effectiveness. <http://pmj.sagepub.com/content/early/2015/09/28/0269216315588728.abstract>

The contribution of undergraduate palliative care education: Does it influence the clinical patient's care?

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 28 September 2015 – There is only indirect evidence palliative care (PC) training at university leads to better clinical care of patients. Almost half of the thirty studies reviewed used a qualitative approach to evaluate learning experiences. Only three were controlled studies and a further one was a cohort study. When students openly express themselves, they agree there is “something” deep as regards the core or the essence of medical practice or nursing. They feel they become better professionals and better prepared for the patients, not only in terms of end-of-life care, but also as regards care, irrespective of the phase of the disease. The inclusion of PC in undergraduate education is a way of providing knowledge, skill, and competences about PC (especially communication) and also improving attitudes toward caring in advanced disease and at the end of life. Different methods of experiential learning, even brief experiences, which bring students into close contact with PC clinical cases or patients, are providing better results. http://journals.lww.com/co-supportiveandpalliative-care/Abstract/publishahead/The_contribution_of_undergraduate_palliative_care.99605.aspx

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 September 2015 – **‘Medical students’ professionalism narratives reveal that experiences with death, dying, or palliative care are more positive than other experiences during their internal medicine clerkship.’** Less than 10% of the narratives were related to death, dying, and palliative care, but the majority was positive. <http://ajh.sagepub.com/content/early/2015/09/30/1049909115609296.abstract>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 30 September 2015 – **‘Physicians’ reflections on death and dying upon completion of a palliative medicine fellowship.’** Patient and family dissatisfaction may result when they are not satisfied with the physician/patient interaction, while the physician may feel he/she worked hard to provide information to the patient and family. New approaches to visual analysis can: 1) Identify significant insights from physicians’ personal and clinical experiences in providing compassionate palliative care and end-of-life care; and, 2) Provide an effective and practical vehicle for communicating with patients, their families, and other professional caregivers. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00507-2/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00507-2/abstract)

Experiences in palliative home care of infants with life-limiting conditions

EUROPEAN JOURNAL OF PEDIATRICS | Online – 28 September 2015 – Palliative treatment of neonates/very young infants with terminal conditions at home seems to be similar to that of older children and feasible in children even with unstable conditions. The spectrum of diagnoses, signs and symptoms varies from older children with swallowing incoordination and artificial nutrition being of particular importance. Data on home-based palliative care of all neonates and infants, who were being taken care of by our paediatric palliative care team between 2007 and 2014, was analysed. A total of 31 patients (pts) were analysed. The majority were diagnosed with congenital malformations or chromosomal abnormalities. Twenty died, five of them in hospital. <http://link.springer.com/article/10.1007/s00431-015-2637-y>

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Corrections & Clarifications

The link to the journal article ‘General practice and palliative care – The Swiss approach’ published in *BAOJ Palliative Medicine* and noted in the issue of Media Watch of 31 August 2015 (#425, p.11), was incorrect. The correct link: http://www.researchgate.net/publication/281268257_General_Practice_and_Palliative_Care_The_Swiss_Approach_BAOJ_Palliative_medicine.

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 September 2015 – ‘**Pediatric primary care involvement in end-of-life care for children.**’ Primary care involvement affected hospice use among older age-groups and home health use among younger age-groups. <http://ajh.sagepub.com/content/early/2015/09/30/1049909115609589.abstract>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 September 2015 – ‘**Community palliative care nurses’ challenges and coping strategies on delivering home-based pediatric palliative care: A qualitative study.**’ The results of this study reinforces the need for integration of pediatric palliative care teaching and communication skills training into all undergraduate health care programs. <http://ajh.sagepub.com/content/early/2015/09/29/1049909115607296.abstract>
- *MÉDECINE PALLIATIVE* | Online – 1 October 2015 – ‘**Pediatric palliative care in France: From yesterday to tomorrow.**’ Based on their personal experiences in intensive care and neurology ... the authors sought to retrace the evolution of the pediatric palliative approach from its origins to the present day. This is done through the lens of both the carers and the parents. Through this unique perspective, they describe the changes they have seen and present the challenges pediatric palliative care will face in the future. <http://www.sciencedirect.com/science/article/pii/S1636652215001233>

N.B. French language article.

Six new countries in European Society for Medical Oncology designated centres of integrated oncology and palliative care

EUROPEAN SOCIETY FOR MEDICAL ONCOLOGY (ESMO) | Online – 26 September 2015 – Patient eligibility for opioids is seriously restricted in some countries, with the highest rate of limited access to palliative care found in the Middle East, followed by Latin America and the Caribbean and Asia. Data are revealed by the ESMO Global Opioid Policy Initiative which identifies barriers to the availability and accessibility of essential pain relieving medication worldwide. But positive signals of policies “tailored” to the needs of patients with advanced cancers are emerging worldwide, supported by 18 new oncology centres in Europe, Asia, Middle East, and Latin America and the Caribbean... This year the group of designated centres has been joined by five new countries, Lebanon, Kuwait, Mexico, Kingdom of Saudi Arabia, Vietnam and Taiwan. http://www.eurekalert.org/pub_releases/2015-09/esfm-snc092615.php

Noted in Media Watch, 23 February 2015, #398 (p.10):

- *SUPPORTIVE CARE IN CANCER* | Online – 14 February 2015 – ‘**How well is palliative care integrated into cancer care? A MASCC, ESMO, and EAPC Project.**’ One hundred eighty-three different institutions completed this survey... Most had palliative care programs and most programs consisted of an inpatient consult service and outpatient clinics. A minority had inpatient palliative care beds and institution supported hospice services. <http://link.springer.com/article/10.1007/s00520-015-2630-z>

N.B. MASCC – Multinational Association of Supportive Care in Cancer; ESMO – European Society for Medical Oncology; EAPC – European Association for Palliative Care. Additional articles on integrating palliative care and oncology are listed in Media Watch of 30 March 2015, #403 (pp.15-16).

The experience of death in techno-scientific societies: Theoretical discussion and consequences for the end-of-life decision-making processes

ILLNESS, CRISIS & LOSS | Online – 28 September 2015 – This article offers a criticism of the generalized idea that contemporary Western Society denies and hides death, and the set of moral recommendations derived from it. The death-denying and death-hiding hypotheses have been proposed in order to explain the changes in the way of facing death after the consolidation of modern medicine. After explaining both hypotheses, the author situates them historically in the context of the origins of bioethics and the

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criticism against techno-science. Offered is a criticism of the assumptions used to justify them. As an alternative to both hypotheses, it is proposed that modern Western Society has created its own way of facing death, namely a techno-scientific approach with particular consequences for the decision-making processes at the end of life. The logical connection established between the hypotheses and the set of moral recommendations is consequently re-examined, arguing for a situated approach to end-of-life dilemmas and decisions. <http://icl.sagepub.com/content/early/2015/09/25/1054137315606837.abstract>

Related:

- *ASIAN BIOETHICS REVIEW*, 2015;7(3):292-305. 'The human spirit and responsive equilibrium: End-of-life care and uncertainty.' An unexpected encounter with the wife of a stroke patient reminded one of the authors of his self-image as an unwelcome neuro-ethical angel of death, often advising relatives against prolonging life because of the risk of unacceptable badness associated with life-prolonging treatment or the lack of any substantial benefit to the patient from such treatment. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/asian_bioethics_review/v007/7.3.gillett.html
- *ILLNESS, CRISIS & LOSS* | Online – 23 September 2015 – 'This is what a clinical death looks like.' Sickness, dying, and ageing are increasingly medicalized, focusing elder quality of life on interventions that the author argues progressively strip autonomy, dignity, and privacy. For elders aged 70-plus years, personal autonomy, or the ability to "author" one's circumstances, is poorly understood, and in clinical settings, often ethically vexatious. What matters to elders, as they approach end of life ... could be more meaningfully understood and supported via an experiential conception of autonomy. <http://icl.sagepub.com/content/early/2015/09/21/1054137315606831.abstract>

Appraisal of cooperation with a palliative care case manager by general practitioners and community nurses: A cross-sectional questionnaire study

JOURNAL OF ADVANCED NURSING | Online – 28 September 2015 – GPs and community nurses are moderately positive about the support from the case manager. Of GPs, 46% rated the case manager as helpful in realizing care appropriate for the patient; for community nurses this was 49%. The case manager did not hinder the process of care and had added value for patients, according to the GPs and community nurses. The tasks of the case manager were associated with whether or not the case manager was helpful in realizing appropriate care, whereas patient characteristics and the number of contacts with the case manager were not. <http://onlinelibrary.wiley.com/doi/10.1111/jan.12818/abstract>

Related:

- *PLOS ONE* | Online – 24 July 2015 – 'Involvement of a case manager in palliative care reduces hospitalisations at the end of life in cancer patients: A mortality follow-back study in primary care.' The GP is more likely to know preferred place of death, the place of death is more likely to be at the home, and less likely to be the hospital, and there are fewer hospitalisations in the last 30 days of life, when cancer patients receive additional support from a case manager compared with patients receiving standard GP care. <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0133197>

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

Rural emergency nurses' end-of-life care obstacle experiences: Stories from the last frontier



JOURNAL OF EMERGENCY NURSING | Online – 23 September 2015 – A questionnaire was sent to 53 rural hospitals [in Utah]. Respondents were asked to share stories that epitomized the obstacles faced while providing end-of-life (EOL) care in the rural emergency setting. The lack of an ideal death (e.g., the nurse personally knows the patient, issues with family members, and unknown patient wishes) was the top obstacle. Other reported obstacles were insufficient emergency department staff and power struggles between nurses and physicians. Rural emergency nurses often pro-

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vide EOL care to friends and family members, whereas their urban counterparts are likely to transfer care to nurses with no relation to the dying patient. Not only does caring for patients whom the nurse knows or is related to cause great distress to rural emergency nurses, but this unfortunately common situation also may prevent patients from receiving the highest quality EOL care. [http://www.jenonline.org/article/S0099-1767\(15\)00438-9/abstract](http://www.jenonline.org/article/S0099-1767(15)00438-9/abstract)

N.B. Additional articles on end-of-life care in rural communities and remote regions are listed in the issues of the Media Watch of 17 August 2015, #423 (p.14), 11 May 2015, #409 (p.13), and 30 June 2014, #364 (p.15).

The social convoy for family caregivers over the course of hospice

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 30 September 2015 – Little is known about the social support networks for those providing this day-to-day care without training. The purpose of this study was to explore changes in family and friend social networks among hospice caregivers over the course of the hospice stay. A statistically significant decline in the caregivers' family network subscale score was found over the four-week period during which they received hospice services, reflecting a possible weakening of their family networks. This result illustrates the potential importance of ongoing comprehensive assessment of caregiver networks and attention to interventions that may assist in capitalizing on both the quantity of support (numbers of individuals asked to help) and the quality of social support (attending to issues of support burden). [http://www.jpmsjournal.com/article/S0885-3924\(15\)00506-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00506-0/abstract)

Noted in Media Watch, 30 March 2015, #403 (p.16):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 26 March 2015 – ‘**The networks of care surrounding cancer palliative care patients.**’ Exploring the care networks surrounding individual patients can be useful for illuminating the extent and complexity of individual patient's care networks; clarifying who is involved and who they communicate with; providing opportunities to see interaction routes that may otherwise be hidden, revealing potentially missing or weak connections; and, highlighting overlaps or gaps in provision. <http://spcare.bmj.com/content/early/2015/03/26/bmjspcare-2014-000782.abstract>

The growth of palliative care in U.S. hospitals: A status report¹

JOURNAL OF PALLIATIVE MEDICINE | Online – 29 September 2015 – This study demonstrates continued steady growth in the number of hospital palliative care programs in the U.S., with almost universal access to services in large U.S. hospitals and academic medical centers. Nevertheless access to palliative care remains uneven and depends on accidents of geography and hospital ownership. Sixty-seven percent of hospitals with 50 or more total facility beds reported a palliative care program. Institutional characteristics were strongly associated with the presence of a hospital palliative care program. Ninety percent of hospitals with 300 beds or more were found to have palliative care programs as compared to 56% of hospitals with fewer than 300 beds. Tax status was also a significant predictor. Not-for-profit hospitals and public hospitals were, respectively, 4.8 times and 7.1 times more likely to have a palliative care program as compared to for-profit hospitals. Palliative care penetration was highest in the New England (88% of hospitals), Pacific (77%), and mid-Atlantic (77%) states and lowest in the west south central (43%) and east south central (42%) states. <http://www.ncbi.nlm.nih.gov/pubmed/26417923>

1. ‘America's Care of Serious Illness: 2015 State-By-State Report Card on Access to Palliative Care in Our Nation's Hospitals,’ Center to Advance Palliative Care & National Palliative Care Research Center, September 2015. <https://reportcard.capc.org/>

Cont.

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>

Noted in Media Watch, 19 August 2013, #319 (p.7):

- *FAMILY PRACTICE NEWS* | Online – 16 August 2013 – ‘**Few states meet palliative care benchmark.**’ Only four states have effective strategies in place to improve access to and knowledge of palliative care (PC) services, the American Cancer Society Cancer Action Network [ACS CAN] reports.¹ The ACS CAN awarded top scores to Connecticut, Maryland, Massachusetts, and Rhode Island using a scoring system that combines grades from the Center to Advance Palliative Care’s national PC report card with actions on model legislation.² The four states passed laws “this session that focus on improving patient quality of life through PC” ... with Maryland finally crossing “the finish line with a PC bill after a 3-year effort.” The six states on the low end of the scoring range were Alabama, Alaska, Arkansas, Delaware, Mississippi, and Oklahoma. <http://www.familypracticenews.com/news/practice-trends/single-article/few-states-meet-palliative-care-benchmark/aa99a285c2ba1f770ae419fa55d66f20.html>
 1. ‘How do you measure up? A Progress Report on State Legislative Activity to Reduce Cancer Incidence and Mortality,’ American Cancer Society Cancer Action Network, August 2013. <http://www.acscan.org/content/wp-content/uploads/2013/08/HDYMU-2013.pdf>
 2. ‘America’s Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals,’ Center to Advance Palliative Care, May 2011. [Noted in Media Watch, 19 September 2011, #219 (p.9)] <http://reportcard.capc.org/pdf/state-by-state-report-card.pdf>

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

Nine in 10 nurses can’t deliver “right level” of palliative care

NURSING IN PRACTICE | Online – 30 September 2015 – Only 10.5% of nurses surveyed by the Royal College of Nursing said that they were always able to deliver the right level of care to patients. The survey of 7,721 nurses also found that 58.5% said that the wishes of patients could not be fulfilled during the last six months of their lives, commonly due to a lack of time, with some also citing a lack of training. The majority (69.4%) of nurses in the community had seen patients having to be taken into hospital in their final hours, against their wishes, because there weren’t the resources to care for them at home. <http://www.nursinginpractice.com/article/nine-10-nurses-can%E2%80%99t-deliver-%E2%80%99Cright-level%E2%80%9D-palliative-care>

Media Watch: Palliative Care Network-e Website

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

New World Health Organization Infographic on Palliative Care

The WHO infographic (see p.18) is available to download in Arabic, Chinese, English, French, Russian and Spanish (accessed 10.02.2015): <http://www.who.int/ncds/management/palliative-care/pc-infographics/en/>

Attitudes and beliefs toward supportive and palliative care referral among hematologic and solid tumor oncology specialists

THE ONCOLOGIST | Online – 28 September 2015 – The present survey of oncology specialists found that hematologic specialists were less likely than were solid tumor specialists to report that they would refer symptomatic patients with newly diagnosed cancer to palliative care. However, both groups were significantly more willing to refer patients early in the disease trajectory if the service name “supportive care” was used instead of “palliative care.” These findings suggest that rebranding might help to overcome the stigma associated with palliative care and improve patient access to palliative care services. <http://theoncologist.alphamedpress.org/content/early/2015/09/28/theoncologist.2015-0240.full.pdf+html>

Selected articles, reports, etc., on the term “supportive” vs. “palliative” care

Noted in Media Watch, 15 July 2013, #314 (p.13):

- *PLOS ONE* | Online – 3 July 2013 – ‘**Diversity in defining end-of-life care: An obstacle or the way forward?**’ The findings [of this study] on the definitions that are in use in a variety of cultural contexts confirmed earlier studies that there is no consensus on the terms for end-of-life (EoLC) nor on the components of its definition. Earlier analyses of definitions related this to the changes in meanings the concept underwent through time. The authors’ analysis has shown that the geographical spread of EoLC – across Europe and more globally – contributes to the diversity in how EoLC is understood. <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0068002>

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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.

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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Noted in Media Watch, 15 April 2013, #301 (pp.14-15):

- *THE ONCOLOGY REPORT* | Online – 10 April 2013 – ‘**Is the moniker “palliative care” too loaded?**’ A telephone survey of one-hundred-and-sixty-nine patients with advanced cancer found that those randomized to hear the term “supportive care” instead of “palliative care” rated significantly higher their understanding, overall impressions and future perceived need for those services. <http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/what-s-in-a-name-is-the-moniker-palliative-care-too-loaded/15b05715fc83fdc88503a88bc9cbfc0e.html>

Noted in Media Watch, 14 January 2013, #288 (p.7):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 11 January 2013 – ‘**Medical oncologists’ perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process. A qualitative study.**’ Although most study participants claimed that early referrals to the service are preferable, oncologists identified several challenges, related to the timing and communication with patients regarding the referral. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8814761&fulltextType=RA&fileId=S1478951512000685>

Noted in Media Watch, 3 September 2012, #269 (p.7):

- *SUPPORTIVE CARE IN CANCER* | Online – 31 August 2012 – ‘**Concepts and definitions for “supportive care,” “best supportive care,” “palliative care,” and “hospice care” in the published literature, dictionaries, and textbooks.**’ Commonly used terms such as “supportive care,” “best supportive care,” “palliative care,” and “hospice care” were rarely and inconsistently defined in the palliative oncology literature. <http://link.springer.com/article/10.1007/s00520-012-1564-y>

Worth Repeating

The solemnity, purpose and ritual of death

“Dying Irish”: Eulogising the Irish in Scotland in *Glasgow Observer* obituaries

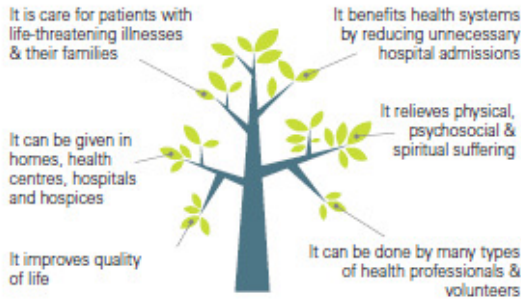
INNES REVIEW, 2010;61(1):76-91. *The Glasgow Observer* newspaper, founded in 1885 by and for the Irish community in Scotland regularly published both lengthy and brief funereal and elegiac obituaries of the Irish in Scotland in the nineteenth and early twentieth centuries. They marshal an impressive, emotive and oftentimes contradictory body of evidence and anecdote of immigrant lives of the kind utilised, and as often passed over, by historians of the Irish in Britain. They contain, however, a unique perspective on the march of a migrant people bespoke of their experiences and, perhaps more importantly, the perception of their experiences in passage, in the host society and ultimately in death. Moreover, the changing sense of Victorian sensibilities over the solemnity, purpose and ritual of death into the Edwardian era finds a moot reflection in the key staples of Irish immigrant obsequies with their stress on thrift, endeavour, piety, charity and gratitude. This article explores *Observer* obituaries from the 1880s to the 1920s to see what they say about the immigrants, their lives, work and culture, the Scots, migration itself, the wider relations between Britain and Ireland, and the place where Irish and British attitudes to death meet in this period. <http://www.eupublishing.com/doi/abs/10.3366/inr.2010.0004>

Noted in Media Watch, 15 February 2010, #136 (p.6):

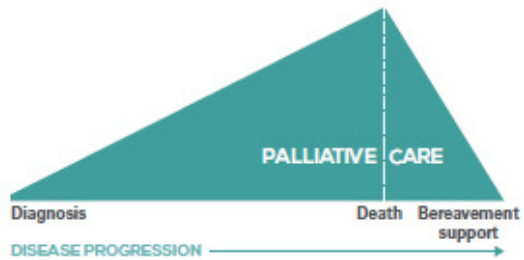
- *THE IRISH TIMES* (Dublin) | Online – 9 February 2010 – ‘**Recognising the beauty of an Irish lament.**’ Whatever has been lost in Irish culture, the tradition of funeral going has not died. Attending funerals remains an integral part of cultural life. Funeral going is psychologically complex. It is comforting to those who mourn, recognition of the life of those who have died, and a celebration of their existence. It allows lament for their departure and acknowledgment of the loss for those who loved them. Funeral attendance is a statement of connection, care, compassion and support. It encircles those who grieve and enriches those who attend because it connects each person there to the profundity of living and the inevitability of death. Funeral attendees witness the raw emotions of grief and the extraordinary capacity of the human spirit to love. Traditional Irish funerals have their own tone, history and vocabulary, well documented in Irish literature, verse, story and song. They have their past and present rituals. <http://www.irishtimes.com/newspaper/health/2010/0209/1224264024663.html>

IMPROVING ACCESS TO PALLIATIVE CARE

WHAT IS PALLIATIVE CARE ?

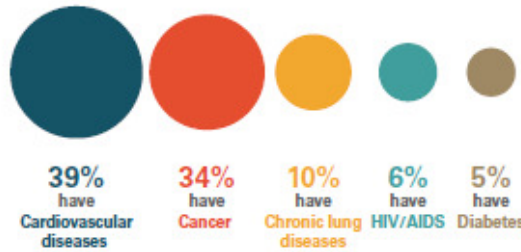


WHEN IS PALLIATIVE CARE NEEDED ?

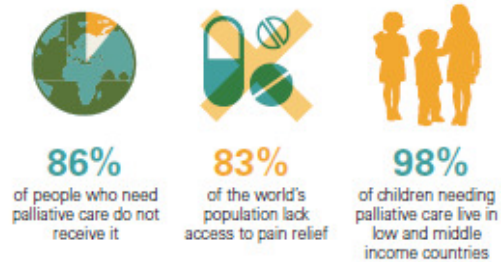


WHO NEEDS IT ?

Of the **40 million** people who need palliative care each year:



WHAT ARE THE GAPS ?



WHAT ARE THE BARRIERS ?



WHAT CAN COUNTRIES DO ?

Implement the 2014 World Health Assembly Resolution 67.19 on palliative care, by:

INTEGRATING PALLIATIVE CARE INTO NATIONAL HEALTH POLICIES



- Revise laws & processes to improve access to opioid pain relief**
- Include palliative care in the training for health workers**
- Provide palliative care services, including through primary health care centres and homes**

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/publications/newsletter/2015/09/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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