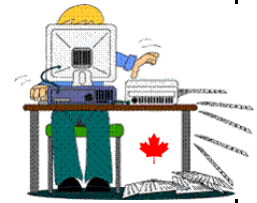


Media Watch...

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

Hoped for integration: Scroll down to [Specialist Publications](#) and 'Palliative care: If it makes a difference, why wait?' (p.15), in *Journal of Clinical Oncology*.

Canada

Political parties need to have positions on future of health care in Canada, says Romanow

THE HILL TIMES (Ottawa, Ontario) | Online – 27 March 2015 – "We need a national pharmacare plan, an active and truly independent Health Council of Canada, comprehensive programs for health and wellness, and a determined enforcement of the Canada Health Act," says former Saskatchewan premier Roy Romanow. "Our Medicare system, quite understandably, has focused a lot of energy and resources on primary and acute care. As the baby boomer generation ages, it becomes ever more pressing that we embrace comprehensive models of care. We must modernize our approach to seniors care, and develop home care and palliative care strategies that honour the dignity and needs of an aging population." <https://www.hilltimes.com/opinion-piece/2015/03/27/political-parties-need-to-have-positions-on-future-of-health-care-in-canada-says/41597>

N.B. Roy Romanow was chair of the Commission on the Future of Health Care in Canada, which published its report, 'Building on Values: The Future of Health Care in Canada,' in November 2002. <http://publications.gc.ca/collections/Collection/CP32-85-2002E.pdf>

Don't want "extraordinary" measures in end-of-life care? Do some advance planning

CTV NEWS | Online – 25 March 2015 – When it comes to end-of-life medical care, treatments most of us think of as ordinary can be deemed extraordinary. Instead of, "Should we resuscitate?" you may face the question, "Should we give her antibiotics for this urinary tract infection?" Questions like these will elicit different answers in different households. And in some, the discussion will be heated. But experts in end-of-life care say these scenarios should be explored early with substitute decision makers – and the broader circles of family and friends. "Sometimes people say 'I don't want heroic measures' and everyone nods their heads and says 'Yeah, OK, sounds good,'" says Dr. James Downar, a palliative care specialist at the University Health Network in Toronto. "(But) if that hasn't translated into an actual medical plan, then all you've got is just a general vague notion of what you should be doing. And that's a problem." It's also common, Downar and others suggest. <http://www.ctvnews.ca/health/don-t-want-extraordinary-measures-in-end-of-life-care-do-some-advance-planning-1.2297212>

Family sues physician, Toronto hospital over no-resuscitation order

ONTARIO | *The Toronto Star* – 25 March 2015 – Toronto physician Dr. Alvin Chang unilaterally placed a "do not resuscitate" order on an elderly patient at Toronto East General Hospital last October against the repeated wishes of her family, a statement of claim filed in court alleges. Canh Luong, who was 94, died later that evening as her family rushed to get a court injunction that would stop the order long enough to have her transferred to another hospital, the family alleges. Chang and Toronto East General committed "wrongful death, abuse of power, negligence and breach of fiduciary duties," reads the claim, which seeks \$1.2 million in damages for four of Luong's family. The allegations have not been proven in court. Barry Swadron, who is representing the family along with lawyer Mercedes Perez, said Chang should have taken the dispute with Luong's family to a provincial body called the Consent & Capacity Board, which hears end-of-life cases such as this and issues orders. <http://www.thestar.com/news/gta/2015/03/25/family-sues-physician-toronto-hospital-over-no-resuscitation-order.html>

Noted in Media Watch, 29 September 2014, #377 (p.1):

- ONTARIO | *The Toronto Star* – 28 September 2014 – **'Stalemate: Deciding life or death.'** The little-known Consent & Capacity Board (CCB) – the only one of its kind in North America – is a working laboratory for the most pressing issue facing Canada's healthcare system: the end of life. When a physician's treatment proposal is challenged by a family member whose loved one can no longer communicate their wishes, doctors can make an application to the CCB. http://www.thestar.com/news/world/2014/09/26/stalemate_deciding_life_or_death.html

Doctors make charter challenge on right to refuse care on religious grounds

ONTARIO | CBC News – 24 March 2015 – Christian medical professionals are challenging Ontario's College of Physicians & Surgeons in court over a policy that requires doctors to provide or at least refer medical services, even when they clash with personal values. In a statement of claim filed in Ontario's Superior Court of Justice, two groups – the Christian Medical & Dental Society of Canada and the Canadian Federation of Catholic Physicians' Societies – and five individual doctors say the college's policy violates their rights under the Charter of Rights & Freedoms. At issue is the Ontario medical regulator's vote earlier this month to update its professional and human rights policy. The new Ontario policy requires doctors unwilling to provide certain care ... to refer patients in good faith to a "non-objecting, available, and accessible" physician. The policy says in medical emergencies, the doctors would be required to perform procedures themselves. <http://www.cbc.ca/news/canada/ottawa/doctors-make-charter-challenge-on-right-to-refuse-care-on-religious-grounds-1.3006462>

Noted in Media Watch, 9 March 2015, #400 (p.2):

- ONTARIO | *The National Post* – 6 March 2015 – **'Doctors who refuse to provide services on moral grounds could face discipline under new Ontario policy.'** Moral or religious convictions of a doctor cannot impede a patient's access to care, the College of Physicians & Surgeons of Ontario said in a 21-3 vote supporting an updated Professional & Human Rights policy. While it does not address physician-assisted death, it could set the stage for conflict with the Canadian Medical Association, whose leaders want to protect doctors against "mandatory referral" when the Supreme Court ... ruling legalizing doctor-hastened dying takes effect... <http://news.nationalpost.com/2015/03/06/doctors-who-refuse-to-provide-services-on-moral-grounds-could-face-discipline-under-new-ontario-policy/>

Of related interest:

- SASKATCHEWAN | *The Star-Phoenix* (Saskatoon) – 26 March 2015 – **'Physicians college discusses right to refuse patient referral on moral grounds.'** The council of the College of Physicians & Surgeons of Saskatchewan is ... considering a conscientious refusal policy, which attempts to balance doctors' freedom of conscience with patients' needs. <http://www.thestarphoenix.com/news/College+Physicians+discusses+right+refuse/10921027/story.html>

Future of health care could be Hospital @ Home

ONTARIO | *Prince Edward County News* – 20 March 2015 – The future of healthcare could be Hospital @ Home if indicators of success in a pilot project of the Prince Edward County Family Health Team continue. Hospital @ Home has cared for 129 patients – 29 of which were diverted from a hospital admission by agreeing to participate in the program, saving a total of 287 hospital days. The program provides a spectrum of services patients would not typically receive from home care, but would have access to in the hospital setting. An overview and details of the pilot were shared ... one year since the official launch. A three-month look at patients admitted to all four Quinte Healthcare Corporation hospitals, with similar ages and treatments as Hospital @ Home patients, showed savings of \$311.31 per day – 42.64% less than hospitalization. <http://countylive.ca/blog/?p=51731>

Of related interest:

- ONTARIO | CBC News – 24 March 2015 – '**Community paramedicine program aims to keep chronic illness patients out of emergency.**' The Community Paramedicine program, which aims to keep people at home and out of the emergency room, allows paramedics to visit patients with chronic and complex illnesses without the prompt of a 911 call. <http://www.cbc.ca/news/canada/sudbury/community-paramedicine-program-aims-to-keep-chronic-illness-patients-out-of-emergency-1.3006968>

Media Watch: Editorial Practice

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

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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

Something Missed or Overlooked?

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

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.

U.S.A.

Facing early death, on their terms

THE NEW YORK TIMES | Online – 28 March 2015 – A national push to have end-of-life discussions before a patient is too sick to participate has focused largely on older adults. When patients are under 18 and do not have legal decision-making authority, doctors have traditionally asked anguished parents to make advanced-care choices on their behalf. More recently, providers have begun approaching teenagers and young adults directly, giving them a voice in these difficult decisions, though parents retain legal authority for underage patients. "Adolescents are competent enough to discuss their end-of-life preferences," said Pamela S. Hinds, a contributor on pediatrics for 'Dying in America,' a 2014 report by the non-profit Institute of Medicine.¹ "Studies

show they prefer to be involved and have not been harmed by any such involvement." There are no firm estimates of the number of young patients facing life-threatening diseases at any given time. Cancer, heart disease and congenital deformities together account for an estimated 11% of deaths among adolescents, about 1,700 per year. <http://well.blogs.nytimes.com/2015/03/28/teen-advance-directive-end-of-life-care/>

Specialist Publications

'Involve children with life limiting conditions in decisions to stop treatment, says new guidance' (p.18), in *British Medical Journal*.

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

Noted in Media Watch, 22 October 2012, #276 (p.9):

- *PROGRESS IN PALLIATIVE CARE* | Online – 15 October 2012 – **'The child's voice in pediatric palliative and end-of-life care.'** Although much is asked clinically and emotionally of children and adolescents receiving treatment for a life-threatening illness, they are not routinely asked how they experience the treatment that is intended to save or prolong their lives. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000035>

Noted in Media Watch, 15 October 2012, #275 (p.3):

- *U.S. NEWS & WORLD REPORT* | Online – 9 October 2012 – **'Teens want voice in end-of-life decisions.'** Teens and young adults who are seriously ill should have a chance to be involved in end-of-life decisions, and a new planning guide – developed especially for this age group – can help, researchers say.^{1,2} <http://health.usnews.com/health-news/news/articles/2012/10/09/teens-want-voice-in-end-of-life-decisions>

1. 'Allowing adolescents and young adults to plan their end-of-life care,' *Pediatrics*, 8 October 2012. <http://pediatrics.aappublications.org/content/early/2012/10/02/peds.2012-0663.abstract>
2. 'Voicing My Choices: A Planning Guide for Adolescents and Young Adults,' *Aging with Dignity*, October 2012. <http://www.agingwithdignity.org/forms/voicingmychoices.pdf>

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>



Report cites need for awareness of end-of-life care options

MASSACHUSETTS | University of Massachusetts Medical School – 26 March 2015 – Public awareness of advance care planning, palliative care and end-of-life options are key to improving end-of-life care in Massachusetts. A Commonwealth Medicine report¹ follows a state law that went into effect December 2014 requiring health care providers to inform patients who have been diagnosed with a terminal illness or may benefit from hospice or palliative care about the options available – palliative care for management of pain and symptoms, and hospice care, which can help patients live in comfort and with dignity during the final months of life. The report details an updated plan of action, including: securing organizational and funding resources to develop and implement a public awareness campaign about advance care planning, palliative care and end-of-life options; ensuring that patients are engaged in advance care planning and health care professionals have the tools they need to prepare them to communicate compassionately with patients; identifying palliative and end-of-life care educational resources in state institutions, and establishing core competencies and building accountability for communication between patients, families and health care providers; developing and disseminating among health care institutions billing and financial system modifications to support patient-centered palliative and end-of-life care; obtaining funding for an entity with broad stakeholder support responsible for ensuring excellence and accountability in

palliative and end-of-life care; and, determining measures for palliative and end-of-life care in clinical settings, and establishing state standards for high-quality care. <http://www.umassmed.edu/news/news-archives/2015/03/umass-medical-school-report-cites-need-for-awareness-of-end-of-life-care-options/>

Uneven terrain: Mapping palliative care need and supply in California

CALIFORNIA HEALTHCARE FOUNDATION | Online – Accessed 19 March 2015 – The availability of specialist palliative care services in hospitals and community settings has increased in California but is still insufficient to meet the demand. For this research, the first step was to generate an estimate of the need for palliative care among individuals in the last year of life. Estimates of need are based on the number of annual deaths in each California county. This data visualization illustrates the estimated need for palliative care in each California county among patients in the last year of life. The maps show the number of palliative care programs (prevalence), the number of patients served annually (capacity), and the sufficiency of supply (need divided by capacity). The data are as of October 2014 and will be updated over the next two years; program sponsors are asked to submit new information, revisions, and comments about their non-hospice palliative care services through these questionnaires. <http://www.chcf.org/publications/2015/02/palliative-care-data>

1. 'Massachusetts Expert Panel on End of Life Report – Looking Forward: 2014 and Beyond,' University of Massachusetts Medical School (Commonwealth Medicine division), March 2015. <http://chpr.umassmed.edu/sites/default/files/End%20of%20Life%20Report.pdf>

Noted in Media Watch, 21 October 2013, #328 (p.4):

- MASSACHUSETTS | *The Boston Globe* – 16 October 2013 – '**End-of-life rules proposed for Massachusetts health facilities.**' Health care-providers often fail to discuss end-of-life care preferences with patients, an omission Massachusetts regulators hope to change with proposed new rules that would require physicians and other staffers at hospitals, nursing homes, and health centers to provide information about choices for people near death. <http://www.boston.com/lifestyle/health/blogs/white-coat-notes/2013/10/16/end-life-rules-proposed-for-massachusetts-health-facilities/vU0leR49koQ2c3fVWARcbJ/blog.html>

Cont.

Of related interest:

- PBS NEWSHOUR | Online – 27 March 2015 – **'How do you want to die? Meet the movement on a mission to make death part of popular conversation.'** A growing national movement to normalize end-of-life discussions among family and friends has gained traction.. <http://www.pbs.org/newshour/bb/new-movement-urges-scary-conversations-death-among-friends-family/>

Many nursing homes fall short at palliative care

NEW YORK MAGAZINE | Online – 24 March 2015 – How good are American nursing homes at palliative care? Given that these are the settings in which many people spend the last days of their lives, it's an important question. A bunch of prior research has shown that in the absence of solid end-of-life planning, many people who are close to death endure painful, intrusive medical procedures that add little to their lives' quality or quantity and that may in some cases actually detract from both. In a new study¹ ... [researchers] ... attempted ... to see how well directors of nursing responded to questions about both their personal knowledge of palliative-care practices and about how their facilities handled these issues... Somewhat alarmingly, 21% of the [1,981] 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. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0393?journalCode=jpm>

Noted in Media Watch, 15 December 2014, #388 (p.12):

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 3 December 2014 – **'Developing palliative care practice guidelines and standards for nursing home-based palliative care teams: A Delphi study.'** The palliative care guidelines and team standards identified in this study may be helpful in providing practical direction to nursing home administrators and staff looking to improve palliative care practice for their residents. [http://www.jamda.com/article/S1525-8610\(14\)00691-4/abstract](http://www.jamda.com/article/S1525-8610(14)00691-4/abstract)

N.B. In this issue of Media Watch are listed some additional articles, noted in past issues of the weekly report, on end-of-life care in nursing homes noted in past issues of the weekly report.

Resuscitation outcomes no worse when families watch doctors work

REUTERS | Online – 24 March 2015 – Letting family members watch while doctors work to bring a loved one back from the brink of death may not hurt patients' odds of survival, a new study suggests.¹ "Hospitals that have been hesitant to set policies that allow families to be in the room during resuscitation should be encouraged that this didn't lead to worse outcomes or errors," said Dr. Zachary Goldberger, the study's lead author from the University of Washington Harborview Medical Center in Seattle. "This is an important opportunity to enhance our end-of-life care for patients who are hospitalized," he told Reuters... The study examined cardiac arrest outcomes for 41,568 patients treated at 252 U.S. hospitals from January 2007-September 2010. Of those, 80 hospitals that treated 13,470 patients had policies allowing families to observe resuscitation. <http://www.reuters.com/article/2015/03/24/us-resuscitation-outcome-family-idUSKBN0MK2KC20150324>

1. 'Policies allowing family presence during resuscitation and patterns of care during in-hospital cardiac arrest,' *Circulation: Cardiovascular Quality & Outcomes*, 24 March 2015. <http://circoutcomes.ahajournals.org/content/early/2015/03/24/CIRCOUTCOMES.114.001272.abstract>

Cont.

Noted in Media Watch, 17 March 2014, #349 (p.16):

- *YALE JOURNAL OF BIOLOGY & MEDICINE*, 2014;87(1):63-72. **'Family presence during resuscitation: Attitudes of Yale-New Haven hospital staff.'** One topic that should be affected by the ... [patient- and family-centered care] ... paradigm is family presence during resuscitation, which continues to be a highly debatable topic with no widespread implementation. Seventy-seven percent of staff members favored allowing the option of family presence during resuscitation. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3941452/>

Noted in Media Watch, 18 March 2013, #297 (p.4):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 March 2013 – **'Family presence during cardiopulmonary resuscitation.'** Relatives [i.e., study participants] who did not witness CPR had symptoms of anxiety and depression more frequently than those who did witness CPR. Family-witnessed CPR did not affect resuscitation characteristics, patient survival, or the level of emotional stress in the medical team, and also did not result in medico-legal claims. http://www.nejm.org/doi/full/10.1056/NEJMoa1203366?query=featured_home

Reimburse doctors for helping patients plan end-of-life care, experts say

REUTERS | Online – 23 March 2015 – Physician incentives are needed to improve end-of-life care in the U.S., health experts said at an Institute of Medicine (IOM) forum. The forum convened ... to discuss action on the recommendations of the IOM's seminal fall [2014] report...¹ "Our current system is not equipped to deal with these challenges," said IOM President Victor Dzau, citing a rising number of elderly with multiple chronic illnesses, too few palliative care services to keep pace with demand, and time pressures that keep providers from having conversations with patients about end of life preferences and values. When people fail to plan for end-of-life care, they may suffer through ultimately futile, invasive and often unwanted treatments, advocates say. Last year, the Centers for Medicare & Medicaid Services [CMS] rejected an American Medical Association request to create a billing code for doctors to use when they spend time helping patients plan for future care. Patrick Conway, chief CMS medical officer, said the coding would be considered this year. <http://www.reuters.com/article/2015/03/23/us-end-of-life-care-reimbursement-idUSKBN0MJ2E920150323>

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

Texas legislature considers more training for caregivers

TEXAS | ABC News – 23 March 2015 – Two bills have been introduced, into Texas legislation, within the last week that aim to provide family caregivers with more hands-on training before their loved one goes home. According to reports there are more than 3.4 million unpaid family caregivers in Texas. The bills, similar, would guarantee that family caregivers receive instruction in medical tasks including wound care, special diets, managing multiple medications or operating equipment. http://www.connectamarillo.com/news/story.aspx?id=1181616#.VRL4tfzF_YQ

Noted in Media Watch, 12 January 2015, #392 (p.4):

- CALIFORNIA | *Kaiser Health News* – 6 January 2015 – **'Lots of responsibility for in-home care providers – but no training required.'** No overall training is required for the more than 400,000 caregivers in California's \$7.3 billion In-Home Supportive Services Program for low-income elderly and disabled residents. The federal government is trying to meet that need by stepping up efforts to expand and train the work force. But for now, there are no federal training requirements for in-home-caregivers. It's up to states to set them in Medicaid-funded programs... <http://kaiserhealthnews.org/news/lots-of-responsibility-for-in-home-care-providers-but-no-training-required/>

N.B. In this issue of Media Watch are listed some additional articles, noted in past issues of the weekly report, on the need to educate and train family caregivers.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | Reuters – 25 March 2015 – **'California bill that would allow assisted suicide passes Senate panel.'** The bill, passed by the Senate Health Committee, would allow patients who are mentally competent and have fewer than six months to live to obtain prescriptions for medication to end their lives. <http://www.reuters.com/article/2015/03/26/us-usa-california-assisted-suicide-idUSKBN0MM02E20150326>

Of related interest:

- CALIFORNIA | *The Los Angeles Times* – 23 March 2015 – **'Assisted-suicide bill would have doctors lie about cause of death.'** If a terminally ill patient takes a legally prescribed overdose, "the cause of death listed on an individual's death certificate who uses aid-in-dying medication shall be the underlying terminal illness." That's not only a corruption of public records integrity, but would materially thwart the very transparency that advocates claim their bill promotes. <http://www.sfchronicle.com/opinion/openforum/article/Assisted-suicide-bill-would-have-doctors-lie-6153765.php>

International

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

Office for National Statistics report explores care quality received by bereaved families

U.K. (England) | The Press Association – 26 March 2015 – One in 10 people suffering a bereavement rated the care their friend or relative had received in the last three months of their life as "poor," according to newly-released data.¹ The Office for National Statistics (ONS) said it found four areas – London, Essex, Greater Manchester and Birmingham and the Black Country [i.e., West Midlands] – were significantly lower than the national average for overall quality of care. In contrast, four areas of England were significantly higher for quality of care: Devon, Cornwall & the Isles of Scilly; Cumbria, Northumberland, Tyne & Wear; Bath, Gloucestershire, Swindon & Wiltshire; and, Wessex. Other findings ... included a "wide variability" in the proportion of people dying in their preferred place, with ... 12% of cardiovascular patients and ... 64% of cancer patients dying in their place of choice. <http://www.careappointments.co.uk/care-news/england/item/36842-ons-report-explores-care-quality-received-by-bereaved-families>

Extract from the Press Association report

The Office for National Statistics said the areas where quality of care was significantly below average corresponded to places of high population density and further research would be useful in investigating a link between urban and rural areas and quality of care.

Specialist Publications

'Quality End-of-Life Care for All (QELCA): The national roll-out of an end-of-life workforce development initiative' (p.11), in *BMJ Supportive & Palliative Care*.

'Hospice Home Immersion Project: Advancing medical education' (p.13), in *International Journal of Clinical Medicine*.

1. 'National Survey of Bereaved People (VOICES) by National Health Service Area Team (England), 2012 to 2013,' Office for National Statistics, March 2015. http://www.ons.gov.uk/ons/dcp171778_399897.pdf

Cont.

Of related interest:

- U.K. (England, Northern Ireland & Wales) | National Council for Palliative Care – 26 March 2015 – ***What to expect when someone important to you is dying: A guide for carers, families and friends of dying people.*** This new guide aims to demystify the dying process so people better understand the changes that can happen to their loved ones in the last days of life. Shaped by people who have experienced the death of someone they were close to, the guide is intended to make the last hours and days of someone's life less distressing for all concerned... http://www.ncpc.org.uk/sites/default/files/What_to_Expect_FINAL_WEB.pdf

End-of-life care in Australia

Aussies patients denied funding for 30 life-saving cancer drugs

AUSTRALIA | News.com.au – 24 March 2015 – Cancer patients want the government to look at crowd funding, a lottery or private health insurance to immediately pay for 30 new high cost treatments that could extend their lives. The nation's drug subsidy scheme doesn't fund the treatments and will consider another 44 new high cost cancer treatments for subsidy this year. Clinicians are warning the lack of access to breakthrough new medicines and the time it takes to approve subsidies will reach crisis point if no action is taken to reform the medicine subsidy process. Cancer patients and their doctors are pushing for an interim program to provide immediate access to the life-saving drugs while experts decide whether they should be subsidised. <http://www.news.com.au/lifestyle/health/aussies-patients-denied-funding-for-30-life-saving-cancer-drugs/story-fneuzlbd-1227277068602>

Home care is bad for the health of the carer: Report

THE NETHERLANDS | Dutch News – 24 March 2015 – Home carers who also hold down a paid job are seeing their own health deteriorate, according to research from the government's socio-cultural planning agency Sociaal en Cultureel Planbureau [socio-cultural planning office]. The agency looked at how often home carers in paid work were off sick and compared it with the period before they took on the home care. Before caring for a family member, 10% of them took two weeks off sick in a year. After taking on home care, the figure rose to 18%. Another finding is that more working people are taking on home care, although in half of cases this amounts to two hours a week. In 2004, 13% of working people were involved in home care. By 2012, the figure had risen to 18%, most of them women between 45 and 65 years old and working 28 hours a week or less. <http://www.dutchnews.nl/news/archives/2015/03/home-care-is-bad-for-the-health-of-the-carer-report/>

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MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE

Please feel free to share this weekly report with your colleagues.
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MW 400: Palliative care in advanced lung disease: The challenge of integrating palliation into everyday care
Download the complete issue (PDF: 450 KB)

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

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

Doctors told "just because you can save babies' lives, doesn't mean you should"

U.K. | *The Telegraph* – 24 March 2015 – Doctors should not always intervene to save the lives of premature babies just because medical advances mean they might succeed, they are ... told in new guidance.¹ The Royal College of Paediatrics & Child Health ... says increased survival rates for infants born between 22 and 25 weeks over the last decade should not be used as a reason to continue treatment in cases where babies were left with a non-existent quality of life. New guidance on life-limiting and life-threatening conditions in children urges doctors to carefully weigh up the likely suffering of the young patient versus the potential benefits of continued treatment. National studies show that between 1995 and 2006, the percentage of babies born between 22 and 25 weeks who survived rose from 40%

to 53%. The authors ... said continued improvements in technology meant sicker infants and children were able to survive. However, they said ... young patients were being forced to endure painful and distressing treatment, which had little chance of securing them survival and a good quality of life. <http://www.telegraph.co.uk/news/health/news/11490213/Doctors-told-just-because-you-can-save-babies-lives-doesnt-mean-you-should.html>

Specialist Publications

'Involve children with life limiting conditions in decisions to stop treatment, says new guidance' (p.18), in *British Medical Journal*.

1. 'Very sick children: Treatment at any cost? New framework to help doctors make tough decisions on end of life care,' The Royal College of Paediatrics & Child Health, March 2015. <http://www.rcpch.ac.uk/news/very-sick-children-treatment-any-cost>

Additional media coverage of The Royal College of Paediatrics & Child Health guidance:

- U.K. | *The Mirror* – 23 March 2015 – **'Terminally ill children to be given a say on whether they want treatment to continue.'** Terminally ill children are to get a bigger say in whether they want to continue treatment. Under controversial new guidelines ... the Royal College of Paediatrics & Child Health sets out when it can be considered no longer in their best interests. <http://www.mirror.co.uk/news/uk-news/terminally-ill-children-given-say-5388159>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- PORTUGAL | *The Portugal News* – 26 March 2015 – **'Deep sleep, not euthanasia, is allowed.'** The chairman of the Portuguese bioethics association has revealed that it is possible in Portugal to have deep, continued sedation for terminal patients, so avoiding suffering, just like the law recently passed in France. <http://theportugalnews.com/news/deep-sleep-not-euthanasia-is-allowed/34376>
- IRELAND | *The Irish Times* (Dublin) – 23 March 2015 – **'Family values: 54% would be willing to help a relative die.'** Given older people are more likely to reflect the values prevalent in their formative years, surely the changing shape of the Irish family is a cultural war zone being fought across the generational divide? Well, exponents of inter-generational conflict are set to be disappointed: the gap between young and old isn't nearly as wide as you might think, based on the results of *The Irish Times*/Ipsos 'Family Values' opinion poll. There are differences in attitudes on some issues, for sure; but the modern generational divide is a much gentler affair. Perhaps the closest there is to a wide generation gap is in relation to the morally controversial issue of euthanasia. Overall, a slender majority of respondents – 54% – agree there are circumstances where they would help a family member to die. Younger people are most likely to agree. Some 66% of those aged 15 to 34 agree, falling to just 37% among the over-55s. <http://www.irishtimes.com/life-and-style/family-values-54-would-be-willing-to-help-a-relative-die-1.2149054>

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

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

Quality End-of-Life Care for All (QELCA): The national roll-out of an end-of-life workforce development initiative

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 26 March 2015 – This article describes the national roll-out and evaluation of the Quality End-of-Life Care for All (QELCA) programme funded by the National Health Service (NHS) National End-of-Life Care Programme. QELCA enables health professionals from acute NHS trusts to experience hospice care and empowers them to improve end-of-life care in their own practice settings. Seventeen acute NHS trusts took part with 21 hospices local to the trusts delivering the programme. Overall, 137 acute nurses participated in the programme, which involved 5 days at the hospice followed by 6 months of action-learning sets. Participants in QELCA progressed from passively identifying problems to actively problem solving and facilitating changes in practice. This attitudinal change has the potential to stimulate and sustain real change in end-of-life care in acute hospitals. QELCA is now being delivered to other members of the multidisciplinary team, including general practitioners. <http://spcare.bmj.com/content/early/2015/03/26/bmjspcare-2014-000816.abstract>

Palliative care for Parkinson's disease: Has the time come?

CURRENT NEUROLOGY & NEUROSCIENCE REPORTS | Online – 22 March 2015 – 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 (e.g., pain, fatigue), 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. As we approach an era of increased life expectancy, increasing co-morbidities among patients, and escalating healthcare costs, physicians must be proactive in focusing on quality of life, reducing medical interventions, and respecting patient autonomy. <http://link.springer.com/article/10.1007/s11910-015-0542-4>

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

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

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.**' An integrated model of care, promoting collaboration between specialist palliative and neurological services, is discussed. <http://pmj.sagepub.com/content/early/2013/07/05/0269216313495287.abstract>

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

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

The pact of silence from the point of view of caregiver of the patient on palliative care

ENFERMERIA CLINICA | Online – Accessed 23 March 2015 – The pact of silence has negative effects on coping with death, quality of life in the last days of life, and mourning. Family caregivers [i.e., study participants] hamper professional-patient communication; use of deceit to conceal the truth; suspicion that the patient knows the truth; the clinician conceals the truth; paternalist attitudes; and, feelings of sadness, grief, resignation, acceptance of the disease. Communication between patients, health care providers, and families should be improved to prevent the pact of silence, and help patients cope with death. <http://europepmc.org/abstract/med/25779960>

N.B. Spanish language article.

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 23 March 2015 – '**Conceptualising psychological distress in families in palliative care: Findings from a systematic review.**' Distress in families in palliative care can be conceptualised and illustrated within a tiered model of distress. <http://pmj.sagepub.com/content/early/2015/03/20/0269216315575680.abstract>

Hospice volunteers: Bridging the gap to the community?

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 26 March 2015 – This article focuses on ... the place that volunteers occupy between the hospice and the community beyond its walls. External changes and pressures in society were impacting on volunteer management, but were viewed as requiring a careful balancing act to retain the "spirit" of the hospice philosophy. Honouring the developmental history of the hospice was vital to many respondents, but viewed less positively by those who wished to modernise. Hospices tend to be somewhat secluded organisations in Britain, and external links and networks were mostly within the end-of-life care arena, with few referring to the wider volunteering and community fields. Volunteers were seen as an informal and symbolic "link" to the local community, both in terms of their "normalising" roles in the hospice and as providing a two-way flow of information with the external environment where knowledge of hospice activities remains poor. The diversity of the community is not fully represented among hospice volunteers. A few hospices [i.e., study participants] had deliberately tried to forge stronger interfaces with their localities, but these ventures were often controversial. The evidence suggests that there is substantial scope for hospices to develop the strategic aspects of volunteering through greater community engagement and involvement and by increasing diversity and exploiting volunteers' "boundary" position more systematically to educate, recruit and raise awareness. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12232/abstract>

What's the diagnosis? Organisational culture and palliative care delivery in residential aged care in New Zealand

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 26 March 2015 – Organisational culture has been shown to impact on resident outcomes in residential aged care (RAC). This is particularly important given the growing number of residents with high palliative care needs. The study ... examined survey results from a convenience sample of 46 managers, alongside interviews with a purposively selected sample of 23 bereaved family members in order to explore the perceptions of organisational culture within New Zealand RAC facilities in one large urban District Health Board. Results of the Organisational Culture Assessment Instrument (OCAI) completed by managers indicated a preference for a "clan" and the structured "hierarchy" culture. Bereaved family interviews emphasised both positive and negative aspects of communication, leadership and teamwork, and relationship with residents. Study results from both managers' OCAI survey scores and next of kin interviews indicate that while the RAC facilities are culturally oriented towards providing quality care for residents, they may face barriers to adopting organisational processes supportive of this goal. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12220/abstract>

Narcotic Drugs & Psychotropic Substances Act

Access to controlled medicines for palliative care in India: Gains and challenges

INDIAN JOURNAL OF MEDICAL ETHICS | Online – Accessed 24 March 2015 – It was in the early 1990s that an appeal was made, both in India and globally, for access to palliative care to be treated as a human rights issue. Over the past few years, India has witnessed robust advocacy efforts which push for the consideration of palliative care and pain management as a human right. Central to this paper is India's Narcotic Drugs & Psychotropic Substances (NDPS) Act, 1985: its genesis, its critique, and the amendments aimed at enhancing access to the NDPS for medical care and research. The author refers to the advocacy efforts in India, particularly the most recent ones, which led to the amendments to the NDPS Act (1985) in February 2014; and the contribution of the global and local human rights discourse on palliative care to these efforts. <http://www.issuesinmedicalethics.org/index.php/ijme/article/view/2197/4701>

Noted in Media Watch, 27 January 2014, #342 (p.6):

- HUMAN RIGHTS WATCH | *World Report 2014* – 23 January 2014 – '**Palliative care: International perspective.**' After a series of positive steps in 2012 to address the suffering of hundreds of thousands of persons with incurable diseases from pain and other symptoms, progress on palliative care in **India** slowed considerably in 2013. The government has so far not allocated a budget to implement India's progressive national palliative care strategy and parliament failed to consider critical amendments to the Narcotic Drugs & Psychotropic Substances Act that would dramatically improve the availability of strong pain medications.¹ More than 7 million people in India require palliative care every year (p.338 of *World Report 2014*). http://www.hrw.org/sites/default/files/wr2014_web_0.pdf

1. The Rajya Sabha, the upper house of parliament, has approved amendments to the Narcotic Drugs & Psychotropic Substances Act (the Drug Act) that the lower house had approved a day earlier. See 'India: Major breakthrough for pain patients,' Human Rights Watch report, 21 February 2014, noted in Media Watch, 24 February 2014, #346 (p.5).

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

Hospice Home Immersion Project: Advancing medical education

INTERNATIONAL JOURNAL OF CLINICAL MEDICINE, 2015;6:158-169 The purpose of the Hospice Home Immersion Project is to provide second year medical students with firsthand experiences of living in the hospice home for 48 hours to answer the question: "What it is like *for me* to live in the hospice home?" The results focus on the students' common themes that include 1) unknown territory; 2) support; 3) role of staff; 4) role of immersion learning in palliative and end-of-life care; 5) facing death and dying; and, 6) clinical pearls. This project humanizes dying and death, solidified student realization that dying is a part of life and what an honor it is to be a part of the care process that alleviates pain, increases comfort, values communication, and human connections. Students report new found skills in patient care such as the 1) importance of physical touch; 2) significance of communication at the end of life for the patient, family, and staff; 3) the value of authenticity and sincerity that comes from being comfortable with oneself, which allows silence to communicate caring; 4) connection with and awareness of the person (rather than their terminal illness) and their family; and, 5) the importance of speaking with patients and their families about end of life plans in advance. Although this is a time intensive experience for the faculty member and the hospice home staff, the depth of learning experienced by the students and opportunities to advance medical education in death and dying are well worth the efforts. file:///C:/Users/Barry/Downloads/IJCM_2015031915422876.pdf

Cont.

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 24 March 2015 – **'The meaning of home at the end of life...'** Whether or not participants deemed space(s) safe or unsafe was closely related to the notion of home. Six themes emerged [in this study]: 1) no place like home; 2) safety, home and the hospital; 3) hospital "becomes" home; 4) home "becomes" hospital; 5) hospital and "connections with home"; and, 6) the built environment. Home is a dynamic concept for people nearing the end of life and is concerned with expression of social and cultural identity including symbolic and affective connections, as opposed to being merely a physical dwelling place or street address. <http://pmj.sagepub.com/content/early/2015/03/24/0269216315575677.abstract>
- *PALLIATIVE MEDICINE* | Online – 24 March 2015 – **'Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: A discrete choice experiment.'** Results [of this study] highlight the importance of pain management, supporting home deaths, and addressing other end-of-life concerns, in addition to efforts to extend life. Differences in willingness to pay of patients and caregivers suggest the need for eliciting patient preferences during treatment decision making as opposed to relying on caregiver input. <http://pmj.sagepub.com/content/early/2015/03/24/0269216315578803.abstract>

Why and how is compassion necessary to provide good quality healthcare?

INTERNATIONAL JOURNAL OF HEALTH POLICY & MANAGEMENT, 2015;4(4):199-201. Recent disclosures of failures of care in the National Health Service in England have led to debates about compassion deficits disallowing health professionals to provide high quality responsive care. While the link between high quality care and compassion is often taken for granted, it is less obvious how compassion – often originating in the individual's emotional response – can become a moral sentiment and lead to developing a system of norms and values underpinning ethics of care. In this editorial, the author argues why and how compassion might become a foundation of ethics guiding health professionals and a basis for ethics of care in health service organisations. <http://eprints.kmu.ac.ir/9083/1/IJHPM29931427830200.pdf>

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 23 March 2015 – **'Dignity and patient-centred care for people with palliative care needs in the acute hospital setting: A systematic review.'** Papers highlighted the many and varied potential threats to dignity for people with palliative care needs in acute settings, including symptom control and existential distress, approaches and models in care provision and healthcare settings and design. Acute hospital staff require adequate training ... and the correct environment in which to deliver dignified and person-centred end-of-life care. <http://pmj.sagepub.com/content/early/2015/03/20/0269216315575681.abstract>

What is important to families in intensive care once a decision has been made to withdraw treatment

INTERNATIONAL JOURNAL OF PALLIATIVE CARE & MEDICINE | Online – 5 March 2015 – How doctors and nurses talk with families about decisions that lead to treatment withdrawal in intensive care is important and has been well explored. However less is known about what family members perceive as important once this decision has been made. This study explores the needs of family members during and after treatment has been withdrawn in intensive care. Whilst family members [i.e., study participants] were able to broadly recollect conversations with doctors and nurses about the decision to withdraw treatment, there were detailed accounts of what was important to family members after that decision was made. In this, family members recalled wanting to: alleviate further suffering, re-establish identity of, and re-connect relationships with, the dying person. Bereaved family members spoke about the activities they undertook to realize these. At interview, family members demonstrated on-going distress about situations perceived as preventing achievement of these. <http://omicsgroup.org/journals/what-is-important-to-families-in-intensive-care-once-a-decision-has-been-made-to-withdraw-treatment-2165-7386.10001212.pdf>

Palliative care: If it makes a difference, why wait?

JOURNAL OF CLINICAL ONCOLOGY | Online – 23 March 2015 – Half of all patients with cancer might be predicted to die as a result of the disease within 5 years. Ask yourself whether an individual patient might die within a year, and you are likely to be incorrect in your estimate. But what is certain is that you will not be able to cure everyone. Palliative care (PC) offers patients and (note) their families a comprehensive package of care by a team of professionals who became experts in solving the difficult and multiple symptoms and problems that usually arise in advanced stages of the disease, helping to achieve comfort and eventually a peaceful death and bereavement. The practice has matured during the last 50 years, and it can be provided together with curative treatment. There are approximately 16,000 PC services worldwide,¹ and fast-growing research demonstrates the effectiveness of interventions, most notably that of home-based models of PC to support patients in their own homes, which is where most would prefer to be cared for and die, with family nearby.² In 2012, after publication of strong evidence from a phase III randomized controlled trial, an American Society of Clinical Oncology provisional clinical opinion recommended consideration of combined standard oncology care and PC early in the course of illness for any patient with metastatic cancer and/or a high symptom burden.³ In 2014, a landmark resolution was passed unanimously at the World Health Assembly that called for all state members to strengthen PC as a component

of integrated treatment within the continuum of care.⁴ The question of when to initiate is central to this hoped-for integration. <http://jco.ascopubs.org/content/early/2015/03/23/JCO.2014.60.5386.full>

Steps clinicians can take

Ask patients about quality of life routinely. For example, "How are your spirits?" and/or "Are you able to do the things you need to do?"

Consider a referral for early PC if you have access to an outpatient consultation service; if you do not have access tell your health system or administrator that you need it.

Talk about PC as "an extra layer of support" that is helpful "at every point in cancer care."

Make discussions about the future a routine part of your practice. Ask (more than once) whether patients want to talk about their prognosis.

Encourage patients to prepare for sudden problems that might occur when they are too sick to make decisions. Establish a medical durable power of attorney.

Help patients and families prepare for end of life care, and encourage them to consider this earlier than they think they will need it. Consider a hospice information visit early.

Source: 'Palliative care: A lifeline to quality of life,' *Journal of Clinical Oncology*, 7 February 2012 [Noted in Media Watch, 13 February 2012, #240 (p.10)]

1. 'Global Atlas of Palliative Care at the End of Life,' World Health Organisation and the Worldwide Palliative Care Alliance, January 2014. [Noted in Media Watch, 3 February 2014, #343 (p.5)] <http://www.thewpca.org/resources/global-atlas-of-palliative-care/>
2. 'Early palliative care for patients with metastatic non-small-cell lung cancer,' *New England Journal of Medicine*, 18 August 2010 [Noted in Media Media, 23 August 2010, #163 (p.8)] <http://www.nejm.org/doi/full/10.1056/NEJMoa1000678>
3. 'American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care,' *Journal of Clinical Oncology*, 6 February 2012 [Noted in Media Watch, 13 February 2012, #240 (p.10)] <http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.abstract>
4. 'Strengthening of palliative care as a component of comprehensive care throughout the life course,' World Health Organization, Geneva, Switzerland, 24 May 2014. http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf

Cont.

Of related interest:

- *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>
- *HEMONC TODAY* | Online – 25 March 2015 – **'Palliative medicine under the microscope: Not every patient with cancer needs palliative care.'** It would be extremely hard to question the benefits of palliation for patients with intractable disease. At a community level, a litany of studies have shown conclusively active treatment is an expensive option that affords little benefit ... to the dying patient, and is effectively and appropriately replaced by timely referral for palliative and then hospice care. That said, the thought all patients with cancer should receive palliative care ... just doesn't make sense to me as clinician with 40 years of experience. <http://www.healio.com/hematology-oncology/palliative-care/news/print/hemonc-today/%7B6e166b0e-604b-47a1-ae4-6ed28bcb5bf4%7D/palliative-medicine-under-the-microscope-not-every-patient-with-cancer-needs-palliative-care>

N.B. The author cites the Oncology Nursing Society's palliative care for people with cancer "position" (December 2014) that recommends "palliative care be provided throughout the treatment continuum" from diagnosis. <https://www.ons.org/advocacy-policy/positions/practice/palliative-care>

Community palliative care in Turkey: A collaborative promoter to a new concept in the Middle East

JOURNAL OF PUBLIC HEALTH MANAGEMENT & PRACTICE | Online – 13 March 2015 – The Middle East has been struggling with basic issues of cancer care, and in specific, palliative care, at the primary health care level in the communities. The Middle East Cancer Consortium designated this issue as the highest priority of its activities in the region. Following basic and advanced courses and national and international workshops, local governments recognized the essentiality of developing palliative care services in their respective countries. As the result of these training activities, in 2010, the Ministry of Health in Turkey initiated a novel program whereby population-based and home-based palliative care teams were developed throughout the country, including peripheral regions in the countries where appropriate care was not available. This initiative led to a dramatic increase in the number of cancer patients receiving palliative care at their homes. http://journals.lww.com/jphmp/Abstract/publishahead/Community_Palliative_Care_in_Turkey_A.99765.aspx

Noted in Media Watch, 11 June 2012, #257 (p.8):

- *ANNALS OF ONCOLOGY*, 2012;23(Suppl3):76-78. **'Turkish community-based palliative care model: A unique design.'** One of the pillars of the Turkish Cancer Control Programme is palliative care. The Pallia-Turk project is population based and organized at the primary level. This means, the whole population [of 70 million] will have the quickest and easiest way for access to palliative care. http://annonc.oxfordjournals.org/content/23/suppl_3/76.abstract

N.B. Turkey was rated 34th (of 40 countries surveyed) in *The Quality of Death: Ranking End-of-life-Care Across the World*, commissioned by the Lien Foundation and published by the Economist Intelligence Unit, 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toplevel.pdf

The development of palliative care services in France (1987-2013)

MÉDECINE PALLIATIVE | Online – 26 March 2015 – Between 1987 and 2013, the number of palliative care (PC) units increased from six to 130, resulting in an increase from 150 to 1,412 PC unit beds. In addition, 431 hospital PC support teams were installed in hospital facilities. The number of PC beds has increased from 232 to 4,663 between 2001 and 2004. Finally, home-based PC support teams have been widely developed since 1997, although the authors noticed a decrease in their number between 2010 and 2013. However, despite this significant development of PC services in France, regional discrepancies have increased over time. Considering the extent and the nature of current PC needs at the population level, France's national end-of-life care strategy should shift from a "palliative care service" vision to an "integrated palliative care" perspective. <http://www.sciencedirect.com/science/article/pii/S163665221500015X>

N.B. French language article

Literature review

A scoping review of bereavement risk assessment measures: Implications for palliative care

PALLIATIVE MEDICINE | Online – 24 March 2015 – Palliative care standards and policies recommend that bereavement support be provided to family caregivers, yet uncertainty surrounds whether support currently offered by palliative care services throughout developed countries meets caregiver needs. The public health model of bereavement support, which aligns bereavement support needs with intervention, may address this gap between policy and practice. In all, 19 measures published between 1982 and 2014 were identified for inclusion in this review, and categorised for use with family caregivers at three points in time – before the patient's death, in the period following the death and for screening of prolonged or complex grief. <http://pmj.sagepub.com/content/early/2015/03/24/0269216315576262.abstract>

Of related interest:

- *PALLIATIVE CARE* | Online – 24 March 2015 – '**Interventions for bereaved parents following a child's death: A systematic review.**' Little evidence of sufficient quality is available to confirm the effects of intervention measures on bereaved parents and siblings following a child's death. Well-designed randomized controlled trials are needed to improve our understanding of the efficacy and implementation of interventions targeting bereaved parents and siblings. <http://pmj.sagepub.com/content/early/2015/03/24/0269216315576674.abstract>

Pediatric palliative care and inpatient hospital costs: A longitudinal cohort study

PEDIATRICS | Online – 23 March 2015 – This study examined the association between inpatient cost and receipt of PPC among high-cost inpatients. The 10% most costly inpatients treated at a children's hospital in 2010 were studied, and factors associated with receipt of PPC were determined. Among patients dying during 2010, the authors compared inpatient costs between PPC recipients and non-recipients. Inpatient costs during the 2-year follow up period between PPC recipients and non-recipients were also compared. Patients were analyzed in 2 groups: those who died and those who survived the 2-year follow-up. Of 902 patients, 86 (10%) received PPC. Technology dependence, older age, multiple chronic conditions, PICU admission, and death in 2010 were independently associated with receipt of PPC. PPC recipients had increased inpatient costs compared with non-recipients during 2010. Among patients who died during the 2-year follow-up, PPC recipients had significantly lower inpatient costs. Among survivors, PPC recipients had greater inpatient costs. When controlling for patient complexity, differences in inpatient costs were not significant. <http://pediatrics.aappublications.org/content/early/2015/03/17/peds.2014-3161.abstract?sid=aef43df6-60ef-4475-810c-6ce842f2c78f>

Cont.

Of related interest:

- *BRITISH MEDICAL JOURNAL* | Online – 24 March 2015 – '**Involve children with life limiting conditions in decisions to stop treatment, says new guidance.**' The views of children who have incurable and life limiting conditions should be actively sought and considered in decisions on whether to continue life prolonging treatment, says new guidance from the Royal College of Paediatrics & Child Health.¹ Although circumstances will differ, children who have had extensive experience of disease and its treatment, such as repeated cycles of chemotherapy, will have more informed views about continuing treatment than an adult facing treatment for the first time, the document says. <http://www.bmj.com/content/350/bmj.h1621>
 1. 'Very sick children: Treatment at any cost? New framework to help doctors make tough decisions on end of life care,' The Royal College of Paediatrics & Child Health, March 2015. <http://www.rcpch.ac.uk/news/very-sick-children-treatment-any-cost>
- *CHILDREN* | Online – 23 March 2015 – '**Families' perspectives of quality of life in pediatric palliative care patients.**' Medical and academic institutions began prioritizing Pediatric Palliative Care (PPC) less than two decades ago. Although policies and institutions claim to improve the Quality of Life (QoL) of PPC patients and their families, family-defined QoL remains ambiguous. The authors identified several factors that primary caregivers considered components of QoL for their children. QoL for PPC patients was defined by primary caregivers as being able to communicate in a respectful, controlled, physically- and socially-comfortable environment. Attempts to improve QoL should focus not only on pain and symptom control, but also on enhancing opportunities for children to communicate and maintain a sense of dignity. <file:///C:/Users/Barry/Downloads/children-02-00131.pdf>
- *INTERNATIONAL JOURNAL OF PALLIATIVE CARE & MEDICINE* | Online – 26 March 2015 – '**Pediatric oncology palliative care: Experiences of General Practitioners and bereaved parents.**' Time pressures GPs faced influenced their level of management with the family during palliative care and bereavement care, and their ability to address their identified learning deficits. Lack of familiarity with the family, coupled with an acknowledgement that it was a rare and could be frightening experience also influenced their level of interaction. There was no consistency in GP practice nor evidence of practice being guided by local or national policies. <http://omicsgroup.org/journals/pediatric-oncology-palliative-care-experiences-of-general-practitioners-and-bereaved-parents-2165-7386.1000214.pdf>
- *JOURNAL OF PEDIATRICS* | Online – 20 March 2015 – '**Pediatric palliative care: Current evidence and evidence gaps.**' Hospice and palliative medicine is an emerging medical subspecialty initially recognized by the American Board of Medical Specialties in 2006. As the Institute of Medicine reported in 2014,¹ health care delivery and the challenges of care at the end of children's lives have evolved significantly over the past 15 years. The last decade has seen the growth of pediatric palliative care (PPC) programs at children's hospitals and a transformation of the field. [http://www.jpeds.com/article/S0022-3476\(15\)00139-0/abstract](http://www.jpeds.com/article/S0022-3476(15)00139-0/abstract)
 1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine, 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/~media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE LINACRE QUARTERLY* | Online – 20 March 2015 – '**Pain medicine and palliative care as an alternative to euthanasia in end-of-life cancer care.**' Patients suffering from terminal cancer often have pain. Some have advocated euthanasia or physician-assisted suicide as a potential way of alleviating this suffering. Further examination of this topic, however, shows this approach may be essentially utilitarian and fail to consider the inherent value of human life. There has been significant development in recent years in the fields of pain medicine and palliative care, which afford alternate means of addressing suffering in this patient population. <http://www.maneyonline.com/doi/abs/10.1179/2050854915Y.0000000003>

Cont.

- *PALLIATIVE MEDICINE* | Online – 23 March 2015 – **'The desire to hasten death: Using grounded theory for a better understanding – "When perception of time tends to be a slippery slope."** The desire to hasten death may be used as an extreme coping strategy to maintain control against anticipated agony. Patients [i.e., study participants] expected health professionals to listen to and respect their experiences. Emerging hypotheses included the following: a) patients try to balance life time and anticipated agony, and the perception of time is distressing in this balancing act; b) anticipated images of agony and suffering in the dying process occur frequently and are experienced by patients as intrusive; c) patients expressing a desire to hasten death are in need of more information about the dying process; and, d) patients wanted their caregivers to listen to and respect their wish to hasten death, and they did not expect the caregivers to understand this as an order to actually hasten their death. <http://pmj.sagepub.com/content/early/2015/03/20/0269216315577748.abstract>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/03/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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