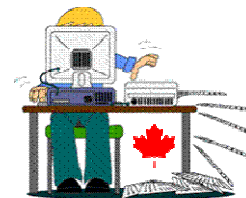


Media Watch...

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

“It is not the fading candle that one expects”: Scroll down to [Specialist Publications](#) and ‘General practitioners’ perspectives on life-preserving versus “letting go” decision-making in end-of-life home care’ (p.17), in *Scandinavian Journal of Primary Health Care*.

Canada

Elder and home care

Ontario moves to scrap troubled health agencies, reorganize primary care

ONTARIO | *The Globe & Mail* – 17 December 2015 – Ontario is moving to scrap the troubled agencies responsible for home care and is proposing changes to the way primary care is organized to make it easier for people to find family doctors and get an appointment when they are sick. The move, made public ... in a discussion paper,¹ comes as the Liberal government faces mounting pressure to make changes to home care following a string of scathing reports... The discussion paper includes no timeline for any of its proposals. At the centre is the expansion of the role played by the province’s Local Health Integration Networks (LHINs) and the elimination of Ontario’s 14 Community Care Access Centres (CCACs)... <http://www.theglobeandmail.com/news/national/ontario-moves-to-scrap-troubled-health-agencies-reorganize-primary-care/article27800107/>

1. ‘Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario: Discussion Paper,’ Ministry of Health & Long Term Care, Ontario Provincial Government, 17 December 2015, file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/9T1OFYF5/discussion_paper_20151217.pdf

Noted in Media Watch, 30 November 2015, #438 (p.2):

- ONTARIO | *The Globe & Mail* – 23 November 2015 – ‘**Ontario plans to target home care in overhaul of health care system.**’ The LHINs and CCACs were the focus of a *Globe & Mail* investigation that found inconsistent standards of care and a lack of transparency that left patients and their families struggling to access services.¹ A report from the Ontario Auditor-General found as little as 61 cents out of every dollar spent by the agencies goes to face-to-face client services, and discovered gaps in the level of care offered across the province.² A second report on home care will be included in the Auditor-General’s annual report in December.³ <http://www.theglobeandmail.com/news/national/ontario-government-to-overhaul-health-care-services/article27447577/>

Cont.

1. See Media Watch of 20 July 2015, #419 (pp.1-2).
2. 'Community Care Access Centres – Financial Operations & Service Delivery,' Office of the Auditor General of Ontario, September 2015. [Noted in Media Watch, 28 September 2015, #429 (p.2)] http://www.auditor.on.ca/en/reports_en/CCACs_en.pdf
3. '2015 Annual Report' (see Chapter 3.1, Community Care Access Centres) Office of the Auditor General of Ontario, December 2015. [Noted in Media Watch, 7 December 2015, #439 (p.2)] http://www.auditor.on.ca/en/reports_2015_en.htm

N.B. See also '2014 Report,' Office of the Auditor General of Ontario, December 2014, and extract on end-of-life care in the province, pp.258-288. [Noted in Media Watch, 15 December 2014, #388 (p.2)] http://www.auditor.on.ca/en/reports_en/en14/308en14.pdf

University of Alberta researcher calls for government support for caregivers

ALBERTA | *The Edmonton Journal* – 16 December 2015 – Canadian governments need to step in and provide support to family caregivers who shoulder a disproportionate amount of the cost of caring for people with long-term disabilities, says a new report by a University of Alberta researcher.¹ Janet Fast, an economist and gerontologist ... said the economic implications affect caregivers and their employers. People providing care often have to cut back the hours at their jobs or frequently miss work. "When those things happen, they will lose pay and they will lose benefits," Fast said in an interview. "Those things have implications for employers as well," she said, noting employers have to pay for replacement staff. "We also know that caregivers' health is affected by caregiving, so if their employer supplies extended health-care benefits, they may rely more heavily on those." Family caregivers also help ease the burden on long-term care facilities. "Their ability to continue to do their unpaid care work is also critical to cost-containment in the health and continuing care sector," Fast said. <http://edmontonjournal.com/news/local-news/university-of-alberta-researcher-calls-for-government-support-for-caregivers>

1. 'Caregiving for Older Adults with Disabilities: Present Costs, Future Challenges,' Research Institute for Public Policy, December 2015. <http://irpp.org/research-studies/study-no58/>

Prince Edward Island paramedics offer palliative care in people's homes

PRINCE EDWARD ISLAND | CBC News – 16 December 2015 – A new program ... allows paramedics to provide palliative care to patients with pain and symptom management at home after hours. Up until now, at-home palliative patients had limited access to after-hours support for pain and anxiety. As a result, many would call 911 and be admitted to hospital. All island paramedics have received the specialized clinical training and education to provide end-of-life care at home. To be eligible, patients must register with the Provincial Integrated Palliative Care Program So far, 170 palliative patients have registered... <http://www.cbc.ca/news/canada/prince-edward-island/palliative-care-patients-cancer-paramedics-1.3367611>

Hospice care for dying kids slowly starting to increase in northeastern Ontario

ONTARIO | CBC News – 14 December 2015 – A hospice in Sudbury has launched a pilot project to provide end-of-life care (EOLC) for teens – and eventually small children – in an effort to help families in the northeast trying to cope with dying children. Maison Vale Hospice executive director Leo Therrien told CBC News there are some differences in care for terminally ill children. "The families play a much bigger role ...," he said. The service, however, comes too late for a woman from Sault Ste Marie, who said there was no pediatric hospice in the northeast in 2014. Amber Scornaiencki was looking for EOLC for her six-year-old daughter who had a brain tumour. Instead of home care, Scornaiencki opted to travel 10 hours from her home in Sault Ste. Marie to Rogers House in Ottawa [a distance of 800 kilometers]. Now there are more options for families. Last May, the adult hospice in the Sault started accepting children. While the Sudbury hospice's pilot program is meant for 12-to-18-year-olds, Therrien said that there are plans for children as young as one year old. <http://www.cbc.ca/news/canada/sudbury/hospice-kids-northeastern-ontario-1.3363843>

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Noted in Media Watch, 1 September 2014, #373 (p.13):

- *PEDIATRICS* | Online – 25 August 2014 – ‘**Characteristics of a pediatric hospice palliative care program over 15 years.**’ Pediatric palliative care has seen the adoption of several service provision models, yet there is minimal literature describing them. Canuck Place Children’s Hospice (in Vancouver, British Columbia) is North America’s first freestanding pediatric hospice. This study describes the characteristics of and services delivered to all children on the Hospice’s program from 1996 to 2010. <http://pediatrics.aappublications.org/content/early/2014/08/19/peds.2014-0381>

At last, a champion for Ontario patients

ONTARIO | *The Toronto Star* – 13 December 2015 – When it comes to power and influence in healthcare circles, doctors rank first, hospitals second, government bureaucrats third, and nurses fourth. Far down the list are patients and caregivers. At last ... that’s about to start changing in Ontario. Health Minister Eric Hoskins has appointed Christine Elliott, former Conservative deputy leader, as Ontario’s first-ever patient ombudsman. Her main role will be to act as a powerful champion for patients, giving a voice to people who feel the healthcare system has failed them. Elliott is a good choice for the job and the Liberal government deserves praise for creating the post. But there is still more that Queen’s Park can do to ensure that patients’ concerns, needs and input are given true consideration when it comes to helping shape healthcare in the years ahead. For decades, the Ontario healthcare system has been planned, operated and overseen by doctors, hospital administrators, health ministry bureaucrats, and executives in agencies such as the Local Health Integration Networks and Community Care Access Centre responsible for home care. Missing is the voice of patients and caregivers. That’s inexcusable, given some 400,000 people are employed in the Ontario health system and several million patients are treated in hospitals, at home and in community settings each year. <http://www.thestar.com/opinion/commentary/2015/12/13/at-last-a-champion-for-ontario-patients-hepburn.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 16 December 2015 – ‘**Liberals call opponents to assisted-dying deadline extension naive.**’ The Liberal government is telling the Supreme Court of Canada that those pushing for speedy implementation of right-to-die policies are strikingly naive about the legislative process. In a submission to bolster its request for a six-month extension, the government says giving effect to a landmark decision on physician-assisted dying will require full parliamentary consideration as well as provincial legislation. Last February, the Supreme Court struck down the prohibition on doctor-assisted death. The court gave the federal government a year to come up with a new law recognizing the right of clearly consenting adults with intolerable physical or mental suffering to seek medical help in ending their lives. The new Liberal government recently asked the court to extend that deadline to early August to ensure “a thoughtful, sensitive and well-informed response.” Several parties have filed arguments on the federal request, and the Supreme Court is likely to issue a ruling soon. <http://www.theglobeandmail.com/news/politics/liberals-call-push-to-meet-assisted-dying-deadline-naive/article27790995/#>
- *THE NATIONAL POST* | Online – 15 December 2015 – ‘**Expert panel fails to find a reassuring route to a euthanasia law.**’ The report of an expert panel on physician-assisted dying¹ ... is meant to provide a guiding path for Canada’s provinces and territories as they plan legislation enabling people to end their own lives. It also highlights again the many troubling aspects of euthanasia that lay along that path. The provinces will need additional legislation to comply with the federal law, and appointed the nine-member panel to offer advice. Among its 43 recommendations are several that carry the potential for intense disagreement. The panel suggests “substitute decision-makers” should have no authority to provide consent in cases where patients lack competence to decide themselves. It leaves it up to doctors to decide competency in many cases, using “existing processes.” It advises against an appeal process in cases where a doctor considers a patient ineligible, but suggests that patients should be free to try another doctor. It recommends against a “reflection period” once a patient chooses to die;

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it feels there should be no need of a doctor on hand for a self-administered death; and it says faith-based institutions can refuse to assist a patient, but must make timely arrangements to transfer the patient to a non-objecting alternative. <http://news.nationalpost.com/full-comment/kelly-mcparland-expert-panel-fails-to-find-a-reassuring-route-to-a-euthanasia-law>

1. 'Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying: Report,' November 2015. Reproduced below is the expert panel's recommendation regarding end-of-life and palliative care. file:///C:/Users/admin/AppData/Local/Microsoft/Windows/NetCache/IE/9T1OFYF5/eagreport_20151214_en.pdf

RECOMMENDATION 1: Provinces and territories, preferably in collaboration with the federal government, should develop and implement a pan-Canadian strategy for palliative and end-of-life care, including physician-assisted dying.

Canadians need better access to quality palliative and end-of-life care, and should be made more aware of the options currently available to them. These were common refrains in the written submissions we received, the face-to-face consultations we conducted, and during our own deliberations.

Many provinces and territories have long been working to improve access to quality palliative and end-of-life care within their own jurisdictions. The Advisory Group strongly recommends that this work be expedited and that provinces and territories develop and implement a pan-Canadian strategy to ensure consistent standards and adequate resources for meeting what should be a national priority.

We also heard some stakeholders suggest that a patient could not truly give free or properly informed consent to physician-assisted dying without first being aware of and having access to adequate palliative care. The Advisory Group understands that the validity of patient consent lies at the heart of the assessment of eligibility for physician-assisted dying and that lack of access to quality palliative care might, in some specific cases, threaten various elements of a valid consent. However, withholding physician-assisted dying from everyone until palliative care is available and offered to all is not the appropriate response, as it denies those who are eligible the right to die in the manner they choose. Instead, society should work tirelessly to improve access to quality palliative care and health care providers should ensure that, in each individual case, any consent to physician-assisted dying is free and informed and made by a competent individual within the constraints of the system.

Despite our recognition of the importance of a pan-Canadian strategy for palliative and end-of-life care, we do not believe the implementation of physician-assisted dying should be delayed. We believe that a better approach is to ardently promote palliative care while ensuring that health care providers are aware of the potential concerns related to patient consent (to physician-assisted dying) and are equipped to effectively address these concerns while respecting patient autonomy. Better palliative care should not be seen as a pre-condition for the development of a system that permits physician-assisted dying, but rather as a complement to improved end-of-life care.

- NEW BRUNSWICK | CBC News – 15 December 2015 – ‘**College of Physicians releases assisted suicide guidelines.**’ A doctor should not have to report a physician assisted death to an independent body, according to new guidelines by New Brunswick’s College of Physicians & Surgeons. The licensing and regulatory body is sending out its thirteen guidelines to doctors across the province... The guidelines also say a physician “may decline to assist a patient in dying if, in the physicians’ opinion, the patient does not meet the criteria.” <http://www.cbc.ca/news/canada/new-brunswick/assisted-dying-physician-new-brunswick-guidelines-1.3365447>

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Media Watch: Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.18.

- *iPOLITICS* | Online – 14 December 2015 – **‘Physician-assisted death should be listed on medical certificates.’** Physician-assisted deaths should be recorded on medical certificates of death, according to a new analysis...¹ The authors of the analysis argue that, in the event physician-assisted death becomes legal, recording it on the death certificate would be a key aspect of oversight and data gathering, which would potentially lead to better research for making informed health policy decisions, as well as let the public know the new system is working properly through oversight and that only those who qualify will get it. If that were the case, it would mean the physical consequences of the lethal drugs would be listed as the immediate cause of death, while the condition that made the person terminally ill would be listed as the underlying cause. Dalhousie University Professor Jocelyn Downie, who co-wrote the article and was a member of the Royal Society of Canada’s expert panel on end-of-life decision-making, says this would be one of the easier areas of physician-assisted death on which to harmonize policies across jurisdictions. There is currently no uniform medical certificate of death across Canada, because it falls under provincial jurisdiction. However, each province and territory requires the immediate cause of death and underlying causes be clearly stated. That means ... any standardizing of the forms would require provincial co-operation. <http://ipolitics.ca/2015/12/14/cmaj-physician-assisted-death-should-be-listed-on-medical-certificates/>

1. ‘Medical certificates of death: First principles and established practices provide answers to new questions,’ *Canadian Medical Association Journal*, 14 December 2015. Access to the article requires a subscription required. <http://www.cmaj.ca/content/early/2015/12/14/cmaj.151130.full.pdf>

Noted in Media Watch, 7 September 2015, #426 (p.1):

- *THE NATIONAL POST* | Online – 4 September 2015 – **‘Medical leaders grapple with new euthanasia dilemma: What to write on the death certificate.’** As Canada inches closer to granting doctors the power to end the lives of consenting patients, medical leaders are grappling with a new dilemma: should deaths by lethal injection be classified “death by natural causes” on death certificates? Quebec’s College of Physicians is considering recommending doctors list the underlying terminal disease as the cause of death in cases of “medical aid in dying” on public death records – and not euthanasia. The college says it wants to ensure life insurance is paid to families in cases of euthanasia and says the province’s assisted-death law will require any doctor who administers euthanasia to report the death to a special oversight body. <http://news.nationalpost.com/health/medical-leaders-grapple-with-new-euthanasia-dilemma-what-should-be-on-the-death-certificate>

Specialist Publications

‘Physician-assisted suicide is not a failure of palliative care’ (p.17), in *Canadian Family Physician*.

‘University of Toronto experts offer recommendations on physician-assisted dying’ (p.17), in *University of Toronto News*.

U.S.A.

New York City Council passes family caregivers’ legislation

STATE OF NEW YORK | *The News & Observer* (Raleigh, New Carolina) – 17 December 2015 – The city council voted to amend the city’s human rights law to make “caregiver status” a protected class. The legislation benefits family members who care for children, the disabled, and the elderly to ensure fair treatment for family caregivers in both the workplace and during the hiring process. <http://www.newsobserver.com/news/business/article50220135.html>

Specialist Publications

‘A blue ocean strategy for palliative care: Focus on family caregivers’ (p.9), in *Journal of Pain & Symptom Management*.

When a baby dies

THE NEW YORK TIMES | Online – 16 December 2015 – Most of the children with life-limiting conditions die with distressing symptoms such as pain or breathlessness that are easily treatable, but not treated because of lack of access to specialists in pediatric pain and palliative care. One main reason for this lack of access, other than too little training for clinicians and hospital leaderships not supporting program development, is that insurance companies do not reimburse this type of medical care sufficiently, even though it helps ensure that children live as long and as well as possible. We cannot always save children from death, but we can do a better job of helping children and their families to “live well”: to save them from needless anxiety, pain

and suffering. At the least, we must be able to look our patients and their loved ones in the eye and promise them that we will do our absolute best to manage distressing symptoms, ensure the best quality of life and take care of them. [http://opinionator.blogs.nytimes.com/2015/12/16/when-a-baby-dies/? r=0](http://opinionator.blogs.nytimes.com/2015/12/16/when-a-baby-dies/?r=0)

Specialist Publications

‘Provision of services in perinatal palliative care: A multicenter survey in the U.S.’ (p.15), in *Journal of Palliative Medicine*.

A hospice for homeless to open in Salt Lake City

UTAH | *Voice Observer* – 16 December 2015 – An average of 50 homeless people die on the streets of Salt Lake City every year. The cause of death for many is a terminal disease. However, soon these people will have a chance to die with dignity. The first hospice house for homeless people is set to open... It will be run by the new non-profit organization... Besides providing food, clothing and a warm bed, The Inn Between will also supply medical needs and companionship. <http://voiceobserver.com/2015/12/16/a-hospice-for-homeless-to-open-in-nbsp-slc.html>

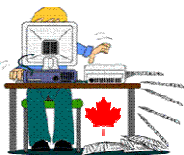
Specialist Publications

‘Hospice use, hospitalization, and Medicare spending at the end of life’ (p.16), in *Journals of Gerontology*.

Noted in Media Watch, 23 November 2015, #437 (p.3):

- UTAH | *Desert News* (Salt Lake City) – 16 November 2015 – **‘Salt Lake City’s homeless deserve hospice care.’** Death is a natural process; since the dawn of humanity, people have been dying at home. But where do homeless people go to die? The shelters are not equipped to deal with the end of life, hospitals can’t keep these patients for weeks or months on end, and most lack insurance to pay for a skilled nursing facility. Without a stable place to live, they end up in and out of the emergency room, straining our city’s fire, police and hospital resources, and eventually dying on the streets or in parks. <http://www.deseretnews.com/article/865641596/Salt-Lake-Citys-homeless-deserve-hospice-care.html>

N.B. Selected articles on end-of-life care for the homeless noted in past issues of Media Watch are listed in the issue of the weekly report of 3 February 2014, #343 (p.4).



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I’ve applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

International

End-of-life care in Taiwan

Legislature passes act giving patients rights on end-of-life care

TAIWAN | Focus Taiwan (Taipei) – 18 December 2015 – The Legislative Yuan passed a patient self-determination act, giving patients in Taiwan the right to stop treatment in five clinical situations at the end of their lives: 1) Terminal patients; 2) Patients with irreversible comas; 3) Patients in a persistent vegetative state; 4) Patients with advanced dementia; and, 5) Patients with other conditions categorized as incurable. The act, said to be the first in its kind in Asia, will be promulgated three years after its announcement, the Ministry of Health & Welfare said. The act stipulates the patient can decide in advance

or after consultations with doctors to refuse end-of-life care when facing the five conditions. <http://focustaiwan.tw/news/aip/201512180029.aspx>

Specialist Publications

'A decade of changes in preferences for life-sustaining treatments among terminally ill patients with cancer' (p.14), in *Journal of National Comprehensive Cancer Network*.

N.B. Taiwan was ranked 6th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

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

National Institute for Health & Care Excellence urges doctors to treat dying patients as individuals

U.K. (England) | BBC News – 16 December 2015 – End-of-life care in England must be tailored to the needs of dying patients rather than a “tick-box approach,” the health watchdog National Institute for Health & Care Excellence (NICE) says. Patients must be treated with respect and compassion ... and doctors should avoid making “snap decisions” about whether someone was dying. The guidance is designed to address misuse of the previous system, the Liverpool Care Pathway (LCP). Charities welcomed the new guidelines – but warned more investment was needed. The (LCP) was introduced in the late 1990s, in an attempt to ensure people had a dignified and comfortable death. Among other things, it involved checklists prompting staff to consider whether invasive procedures, drips and drugs should be withdrawn from people in the last stages of life. But it was phased out last year after a government-commissioned review revealed serious concerns that it was being used in the wrong way, leading

to a “tick-box” culture. The new wide-ranging guidelines¹ – the first national guidelines to be introduced in England – cover many of the same key principles as the LCP. While NICE acknowledged the majority of people are given good care, the watchdog called for a stronger focus on individual plans for each patient, saying their wishes and those of their family must be central. <http://www.bbc.com/news/health-35094342>

Specialist Publications

'Improving primary palliative care in Scotland: Lessons from a mixed methods study' (p.9), in *BMC Family Practice*.

'Care of adults in the last days of life: Summary of National Institute for Health & Care Excellence guidance' (p.11), in *British Medical Journal*.

1. 'Care of dying adults in the last days of life,' National Institute for Health & Care Excellence, December 2015. <https://www.nice.org.uk/guidance/ng31>

Related:

- SCOTLAND (Scotland) | STV News (Glasgow) – 18 December 2015 – **‘Everyone to have palliative care access, pledges Scottish Government.’** Palliative care will be made available to every Scot, regardless of diagnosis, in a new government strategy¹ ... backed by a £3.5 million investment ... addressing what is described as “one of the most challenging issues of the day.” It reveals the Scottish Government’s plans to provide care for all over the next five years, regardless of age, diagnosis, socio-economic background or postcode. <http://news.stv.tv/scotland/1336402-everyone-to-have-palliative-care-access-pledges-scottish-government/>
 1. ‘Strategic Framework for Action on Palliative and End-of-Life Care,’ Scottish Government, December 2015. <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/BXO49UAX/00491388.pdf>
- U.K. (Northern Ireland) | *Belfast Live* – 17 December 2015 – **‘Marie Curie gains cross-party support for new charter that promotes the needs of terminally ill people.’** The leadership of Northern Ireland’s five main political parties joined forces to officially signal their endorsement of leading palliative care charity, Marie Curie’s, charter for people living with any terminal illness. Marie Curie’s ‘Charter for People with a Terminal Illness’ in Northern Ireland aims to raise awareness of how someone with a terminal illness should be treated and consequently start to address some of the barriers that can prevent people accessing the care they need, namely what palliative care is and what services are available. <http://www.belfastlive.co.uk/news/health/marie-curie-gains-cross-party-10614387>
- U.K. (Wales) | Wales Online – 16 December 2015 – **‘Lack of support for carers could lead to a “crisis” in Wales and the rest of the U.K., report warns.’** There will be a “crisis in care” for people with a terminal illness unless more is done to support their carers... A U.K.-wide report looks at the contribution carers make and the impact it has on their own wellbeing.¹ The report found that many unpaid carers don’t see themselves as carers, which often results in them taking on the financial burden and missing out on vital support. <http://www.walesonline.co.uk/news/health/lack-support-carers-could-lead-10608194>
 1. ‘Hidden Costs of Caring,’ Marie Curie, December 2015. <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/BXO49UAX/hidden-costs-of-caring.pdf>

Burial rites

How can we wake our father in a nursing home?

U.K. (Northern Ireland) | BBC News – 14 December 2015 – The traditional Irish wake is a gentle leave taking. It is a time for the soft flicker of candles, a crucifix, and crisp white linen cloths. The loved one’s body is laid out in a quiet room; clocks are stopped at the moment of death, blinds are drawn down, friends and neighbours gather. It is a long night’s vigil – a watch over the dead one. It is a time to weep, but also a time to smile and share a parting glass to celebrate the life that has passed. Tea is served and more tea and more tea and whiskey and mountains of sandwiches are handed out to visitors. They stand shoulder-to-shoulder with the family in the face of loss. But how can you have a traditional wake in a nursing home? <http://www.bbc.com/news/uk-northern-ireland-34763543>

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. <http://www.irishtimes.com/newspaper/health/2010/0209/1224264024663.html>

[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>

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

Is death “the great equalizer”?

The social stratification of death quality in the U.S.

ANNALS OF THE AMERICAN ACADEMY OF POLITICAL & SOCIAL SCIENCES, 2016;663(1):331-354. The author focuses on six core components of a “good death”: 1) Pain and symptom management; 2) Acceptance; 3) Medical care that is concordant with one’s preferences; 4) Dying at home; 5) Emotional preparation; and, 6) Formal preparations for end-of-life care. Analyses are based on four data sets spanning the 1980s through 2010s, a period marked by rising economic inequalities. The author found evidence of socioeconomic status disparities in two outcomes only: pain and advance care planning, widely considered an important step toward a “good death.” Implications for health care policy and practice ... are discussed. <http://ann.sagepub.com/content/663/1/331.short>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 17 December 2015 – ‘**A blue ocean strategy for palliative care: Focus on family caregivers.**’ In a short 10 years, specialty palliative care (PC) has grown exponentially in the U.S., evolving from an inpatient service found in just a few, early-adopter centers to an integrated in- and outpatient interdisciplinary care team operating in two-thirds of the 5,600 U.S. hospitals. The Center to Advance Palliative Care estimates that more than six million patients were touched by PC in 2014, only a few years removed from the dark cloud of “death panels” that greatly distorted American public perception. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00967-7/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00967-7/abstract)

Improving primary palliative care in Scotland: Lessons from a mixed methods study

BMC FAMILY PRACTICE | Online – 10 December 2015 – Since 2012, all GP practices across Scotland have been supported to take a systematic approach to end-of-life care by helping them to identify more patients for palliative care (PC) through a Palliative Care Directed Enhanced Service (DES). Data were received from 512 practices in nine Scottish Health Boards for the 2012-2013 DES, and 638 practices in 11 Health boards for 2013-2014. A sample of 90 of the returns for 2012-2013 was selected for qualitative analysis: 72% of patients who died of cancer were listed on the PC register before death while 27% of patients who died as a result of non-malignant conditions were listed... In 2013-2014, cancer identification remained the same but identification of people dying with other long-term conditions had improved to 32.5%. The authors identified several key issues needed to improve PC in the community: 1) The need for training to identify patients with PC needs (particularly non-cancer); 2) Communication skills training; 3) Improvements in sharing information across the NHS; 4) Under resource of – and lack of – coordination with district nurses; 5) Improvements in information technology; and, 6) Tools for working with enlarged PC registers. <http://link.springer.com/article/10.1186/s12875-015-0391-x>

Noted in Media Watch, 7 May 2012, #252 (p.7):

- *BRITISH JOURNAL OF GENERAL PRACTICE*, 2012;62(598):e344-e352. ‘**Are U.K. primary care teams formally identifying patients for palliative care before they die?**’ Most patients with advanced progressive illnesses, especially those with non-malignant disease, are not being formally identified for a palliative care (PC) approach before they die. Those identified are more likely to benefit from coordinated care and may be more likely to die at home. In total, 29% of patients who died were recorded as being on the practice PC register before death. Two-thirds of patients with cancer were recorded on the register, but for those with non-malignant conditions only around 20% had any PC documented. <http://bjgp.org/content/62/598/e344>

What makes an academic paper useful for health policy?

BMC MEDICINE | Online – 17 December 2015 – Evidence-based policy ensures that the best interventions are effectively implemented. Integrating rigorous, relevant science into policy is therefore essential. Barriers include the evidence not being there; lack of demand by policymakers; academics not producing rigorous, relevant papers within the timeframe of the policy cycle. This article addresses the last problem. Academics underestimate the speed of the policy process, and publish excellent papers after a policy decision rather than good ones before it. To be useful in policy, papers must be at least as rigorous about reporting their methods as for other academic uses. Papers which are as simple as possible (but no simpler) are most likely to be taken up in policy. The accurate synthesis of existing information is the most important single offering by academics to the policy process. Since policymakers are making economic decisions, economic analysis is central, as are the qualitative social sciences. Models should, wherever possible, allow policymakers to vary assumptions. Objective, rigorous, original studies from multiple disciplines relevant to a policy question need to be synthesized before being incorporated into policy. <http://bmcmecine.biomedcentral.com/articles/10.1186/s12916-015-0544-8>

Related:

- *BRITISH MEDICAL JOURNAL* | Online – 14 December 2015 – ‘**Use of positive and negative words in scientific PubMed abstracts between 1974 and 2014: Retrospective analysis.**’ Although it is possible that researchers have adopted an increasingly optimistic writing approach and are ever more enthusiastic about their results, another explanation is more likely: scientists may assume that results and their implications have to be exaggerated and overstated in order to get published. The authors’ finding that scientific abstracts use more overt positive language is also probably related to the emergence of a positive outcome bias that currently dominates scientific literature. There is much pressure on scientists in academia to publish as many papers as possible to further their careers. As a result, we may be afraid to break the bad news that many studies do not result in statistically significant or clinically meaningful effects. Currently, most research findings could be false or exaggerated, and research resources are often wasted. Overestimation of research findings directly impairs the ability of science to find true effects and leads to an unnecessary focus on research marketability. This is supported by a recent finding that superlatives are commonly used in news coverage of both approved and non-approved cancer drugs. The consequences of this exaggeration are worrisome since it makes research a survival of the fittest: the person who is best able to sell their results might be the most successful. It is time for a new academic culture that rewards quality over quantity and stimulates researchers to revere nuance and objectivity. Despite the steady increase of superlatives in science, this finding should not detract us from the fact we need bright, unique, innovative, creative, and excellent scientists. <http://www.bmj.com/content/351/bmj.h6467>
- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 17 December 2015 – ‘**Peer-review fraud – hacking the scientific publication process.**’ In August 2015, the publisher Springer retracted 64 articles from 10 different subscription journals “after editorial checks spotted fake email addresses, and subsequent internal investigations uncovered fabricated peer review reports,” according to a statement on their website. The retractions came only months after BioMed Central, an open-access publisher also owned by Springer, retracted 43 articles for the same reason. “This is officially becoming a trend,” Alison McCook wrote on the blog Retraction Watch, referring to the increasing number of retractions due to fabricated peer reviews. <http://www.nejm.org/doi/full/10.1056/NEJMp1512330>

N.B. Retraction Watch: <http://retractionwatch.com/>

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

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

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

Care of adults in the last days of life: Summary of National Institute for Health & Care Excellence guidance

BRITISH MEDICAL JOURNAL | Online – 16 December 2015 – In 2013, the U.K. Department of Health called for the abolition of the Liverpool Care Pathway, which was designed to bring a standard of care for the dying from the hospice sector into other settings. This move was provoked by an independent review, which showed that the pathway had been misused and misinterpreted as a tick box exercise. It called for individualised care plans and better staff training in all aspects of end of life care. Care of dying people should be based on evidence and must be tailored to individual needs and wishes, rather than being protocol driven. This article summarises the most recent recommendations from the National Institute for Health & Care Excellence.¹ **What you need to know:** Seek support from more experienced staff, including those in palliative care services, if you are unclear about any aspect of care of the dying adult, including the recognition of dying and symptom management; Assess for and treat any reversible causes of distressing symptoms or signs in people in the last few days of life – for example, uncontrolled pain or dehydration causing agitation; and, Regularly review the care plan (usually daily), discuss any changes with the dying person and those important to the person; make clear documentation in the medical notes. **What's new in this guidance?** Guidance on recognition of dying, with the uncertainty around this, and encouragement of open communication and shared decision making; Maintaining hydration (including oral care) as a priority, and offering fluids up until the end of life, regardless of the care setting; and, Emphasis on individualised prescribing for current and anticipated symptoms, avoiding undue sedation or other side effects. <http://www.bmj.com/content/351/bmj.h6631>

1. 'Care of dying adults in the last days of life,' National Institute for Health & Care Excellence, December 2015. <https://www.nice.org.uk/guidance/ng31>

Evaluating a human rights-based advocacy approach to expanding access to pain medicines and palliative care: Global advocacy and case studies from India, Kenya, and Ukraine

HEALTH & HUMAN RIGHTS JOURNAL, 2015; 17(2):149-165. Attributing policy change to one specific organization, intervention or strategy is often impossible and can be counter productive. Moreover, the long-term nature of policy or legal change makes it difficult to track the specific antecedents and contributions of actions that set the stage for later potentially more visible work. Efforts by coalitions, which bring diverse expertise, authority, and perspectives, can provide critical momentum to the development of new norms and can increase pressure on international organizations to change priorities and practices. In this case, the involvement of mainstream human rights organizations in advocacy around access to palliative care (PC) lent credibility and specificity to the concept and helped generate a broad acceptance that PC is indeed a right. The authors efforts to advance an understanding and acceptance of access to PC as an element of the right to health were aided by recognition of the relationship between this right and two fundamental principles long recognized within human rights movements. First, the right to be free of unnecessary suffering is consistent with the principle of dignity, on which human rights are based. Secondly, the *de facto* denial of access to pain relief, where it causes severe pain and suffering, can be considered cruel, inhuman, and degrading treatment. Using testimony from individuals and their families ... provided vivid support of both the loss of dignity among people suffering chronic pain and the inhuman and degrading consequences of the lack of access to pain relief. A human rights-based advocacy approach provided new tools and tactics to complement the traditional skill-building provided by PC advocates. <http://www.hhrjournal.org/2015/12/evaluating-a-human-rights-based-advocacy-approach-to-expanding-access-to-pain-medicines-and-palliative-care-global-advocacy-and-case-studies-from-india-kenya-and-ukraine/>

N.B. India was ranked 67th, Kenya 63rd and Ukraine 69th, respectively, of the 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf.

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Related:

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, 2015;29(4):412-415. '**Pain, palliative care, and compassion in India.**' An estimated one million new cases of cancer occur each year in India, with over 80% presenting at the point at which the disease is incurable. This narrative includes five case studies exploring differing aspects of palliative care: 1) Pain management; 2) The difficulties faced in accessing morphine; 3) The importance of compassion in end-of-life care; and, 4) The psychological effects on families. They illustrate the degree of suffering some patients and families face, and the relatively simple measures that can be taken to alleviate this. <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/9T1OFYF5/15360288.2015.1101642.pdf>

Patients' and families' perspectives of patient safety at the end of life: A video-reflexive ethnography study

INTERNATIONAL SOCIETY FOR QUALITY IN HEALTH CARE | Online – 14 December 2015 – For dying people, iatrogenic harm is not regarded as “one off” incidents. Rather, harm is experienced as a result of an unfolding series of negative events. Critically, iatrogenic harm is emotional, social and spiritual and not solely technical – clinical misadventure and is inextricably linked with feeling unsafe. Thus, patient safety extends beyond narrowly defined technical – clinical parameters to include interpersonal safety. Current approaches to patient safety do not address fully the needs of dying patients and their families. Patients and their families regard poor communication with and by health professionals to be harmful in and of itself. <https://intqhc.oxfordjournals.org/content/early/2015/12/13/intqhc.mzv095>

Pediatric palliative care

Healthcare users' experiences of communicating with healthcare professionals about children who have life-limiting conditions: A qualitative systematic review protocol

JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS, 2015;13(11):33-42. The prospect of the death of a child from an incurable medical condition is harrowing, yet finding a way to discuss this prospect is crucial to maximize the quality of life for such children and their families. High-quality communication is well recognized as a core skill healthcare professionals need to maximize the quality of care they provide. This skill is valued by service users [i.e., children who have life-limiting conditions and also their families], who consistently rate it as one of the highest priorities for the care they receive. Evidence suggests, however, that healthcare professionals can feel ill-equipped or uncomfortable communicating with and about such children. Therefore, it is important to understand what represents high-quality communication and what is involved in accomplishing this within pediatric palliative care. The objective of this review is to identify and synthesize the best international qualitative evidence on healthcare users' experiences of communication with healthcare professionals about children who have life-limiting conditions. <http://www.joannabriggslibrary.org/index.php/jbisrir/article/view/2413/2732>

Related:

- *CLINICAL ETHICS* | Online – 18 December 2015 – '**The zone of parental discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child.**' Dealing with situations where parents' views about treatment for their child are strongly opposed to doctors' views is one major area of ethical challenge in paediatric health care. The traditional approach focuses on the child's best interests, but this is problematic for a number of reasons. <http://cet.sagepub.com/content/early/2015/12/17/1477750915622033.abstract>
- *NURSING CHILDREN & YOUNG PEOPLE*, 2015;27(10):13. '**Competing issues did not override best interests.**' Making decisions for – and with – children, young people and their families that are reaching the end of life is a challenging and complex matter. An individualised approach to each child's unique situation is required, however there are some commonalities between cases that children and families might expect. <http://journals.rcni.com/doi/abs/10.7748/ncyp.27.10.13.s17?journalCode=ncyp>

A novel interprofessional approach to end-of-life care education: A pilot study

JOURNAL OF INTERPROFESSIONAL CARE, 2015;29(6):643-645. Navigating the biomedical, emotional, and logistical complexity of end-of-life (EOL) care requires seamless interprofessional teamwork. Unfortunately, EOL care, interprofessional collaboration, and the role of support services such as hospice are not adequately emphasized in nursing and medical curricula. This article describes a student-run program, entitled the "HeArt of Medicine," which was designed to foster a reflective and collaborative approach to EOL care. The program consists of three workshops with a novel blend of art, science, and practical information, highlighting the need for interprofessional teamwork. Participants were surveyed before and after the workshops on their attitudes toward EOL care. Composite participant scores after workshops demonstrated increased comfort with and knowledge of EOL care topics. The results show that this program has had a positive impact on participants' knowledge, comfort, and collaboration in EOL settings. <http://www.tandfonline.com/doi/abs/10.3109/13561820.2015.1041585>

Related:

- *CANADIAN FAMILY PHYSICIAN*, 2015;61(12):e577-e582. '**Are family medicine residents adequately trained to deliver palliative care?**' The findings from this qualitative study suggest that there are important benefits and detriments to limiting palliative care (PC) training for family medicine residents (FMRs) to a specialized PC setting. Contrary to intentions, PC education for FMRs might disengage them by reinforcing a notion that PC is a specialized area of medicine. Fortunately, FMRs highlight potential changes such as increasing access to family medicine mentors who practise PC, teaching pragmatic skills on how to incorporate PC into one's practice, and improving access to both continuing professional PC education and PC specialists. These changes might better prepare residents to overcome obstacles in the future, underscoring tangible opportunities for improvement in PC education. <http://www.cfp.ca/content/61/12/e577.full>

Media Watch: Editorial Practice

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

Distribution

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

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Something Missed or Overlooked?

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

Medically inappropriate or futile treatment: Deliberation and justification

JOURNAL OF MEDICINE & PHILOSOPHY | Online – 17 December 2015 – This paper reframes the futility debate, moving away from the question “Who decides when to end what is considered to be a medically inappropriate or futile treatment?” and toward the question “How can society make policy that will best account for the multitude of values and conflicts involved in such decision-making?” It offers a pragmatist moral epistemology that provides us with 1) A clear justification of why it is important to take best standards, norms, and physician judgment seriously; and, 2) A clear justification of why ample opportunity must be made for patients, families, and society to challenge those standards and norms. <http://jmp.oxfordjournals.org/content/early/2015/12/16/jmp.jhv035.abstract>

Physicians’ professionally responsible power: A core concept of clinical ethics

JOURNAL OF MEDICINE & PHILOSOPHY | Online – 14 December 2015 – The gathering of power unto themselves by physicians, a process supported by evidence-based practice, clinical guidelines, licensure, organizational culture, and other social factors, makes the ethics of power – the legitimation of physicians’ power – a core concept of clinical ethics. In the absence of legitimation, the physician’s power over patients becomes problematic, even predatory. As has occurred in previous issues of this journal, the papers in the [upcoming] 2016 clinical ethics issue bear on the professionally responsible deployment of power by physicians. This introduction explores themes of physicians’ power in papers from an international group of authors who address [for example] autonomy and trust, the virtues of perinatal hospice, euthanasia of patients with dementia in Belgium, and a pragmatic approach to clinical futility. <http://jmp.oxfordjournals.org/content/early/2015/12/14/jmp.jhv034.abstract>

End-of-life care in Taiwan

A decade of changes in preferences for life-sustaining treatments among terminally ill patients with cancer

JOURNAL OF NATIONAL COMPREHENSIVE CANCER NETWORK, 2015;13(12):1510-1518. The authors identified seven preference classes: 1) Uniformly preferring; 2) Uniformly rejecting; 3) Uniformly uncertain; 4) Favoring nutritional support, but rejecting other treatments; 5) Favoring nutritional support, but uncertain about other treatments; 6) Favoring intravenous nutritional support with mixed rejection of or uncertainty about other treatments; and, 7) Preferring life-sustaining treatments (LST), except intubation with mechanical ventilation. Probability of class membership decreased significantly over time for the uniformly preferring class (15.26%-8.71%); remained largely unchanged for the classes of uniformly rejecting (41.71%-40.54%) and uniformly uncertain (9.10%-10.47%), and favoring nutritional support but rejecting (20.68%-21.91%) or uncertain about (7.02%-5.47%) other treatments, and increased significantly for the other two classes. Identifying LST preference patterns and tailoring interventions to the unique needs of patients in each LST preference class may lead to the provision of less-aggressive end-of-life care. <http://www.jnccn.org/content/13/12/1510.short>

Factors influencing Australian general practitioners’ clinical decisions regarding advance care planning: A factorial survey

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 16 December 2015 – An experimental vignette study pseudo-randomly manipulated factors thought to influence decision-making regarding advance care planning (ACP). Patient-level factors included gender, age, type of disease, medical severity, openness to ACP, doctor-patient relationship, and family support. An accompanying demographic survey assessed health professional-level factors, including gender, years of experience, place of training, place of practice, caseload of patients with ACP, direct personal experience in ACP and self-reported attitudes towards ACP. Seventy GPs were recruited, and each completed six unique vignettes, providing ratings of

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patient need for ACP (NeedACP), importance of initiating ACP in the coming months (ImpACP) and likelihood of initiating ACP at the next consultation (LikelyACP). Older patients, with malignant or cardiovascular disease, severe clinical presentations, good doctor-patient relationship, female gender and poor family support were more likely to receive prompt ACP. Positive GP attitudes towards ACP were associated with greater likelihood of initiating ACP promptly. Patients with presentations suggesting higher mortality risk were identified as being in need of ACP; however, the likelihood of initiating ACP was sensitive to GP attitudes and psychosocial aspects of the doctor-patient interaction. Training materials aimed at encouraging GP involvement in ACP should target attitudes towards ACP and communication skills, rather than focusing solely on prognostic risk. [http://www.jpsmjournal.com/article/S0885-3924\(15\)00962-8/abstract](http://www.jpsmjournal.com/article/S0885-3924(15)00962-8/abstract)

Lessons learned from a palliative care-related communication intervention in an adult surgical intensive care unit

JOURNAL OF PALLIATIVE CARE & MEDICINE | Online – 1 December 2015 – A 7-day trigger identified a high-morbidity, high-mortality surgical intensive care unit (SICU) patient population likely to benefit from proactive communication and palliative care (PC). Moreover, this trigger criteria was widely accepted by surgical stakeholders and simple to implement. However, the logistical burden associated with arranging multi-disciplinary meetings and the difficulty in directing meeting content caused the study team to halt the intervention. In general, SICU clinician time investment and willingness (and ability) to conduct a PC-related conversation were key barriers; in particular, physicians (intensivists and surgeons) favoured shorter meetings and less structure to the discussion, though doing so typically led to less family involvement in meetings and less frequent discussion of prognosis or other palliative medicine-related topics. <http://www.omicsgroup.org/journals/lessons-learned-from-a-palliative-care-related-communication-intervention-in-an-adult-surgical-intensive-care-unit-2165-7386-1000240.pdf>

Provision of services in perinatal palliative care: A multicenter survey in the U.S.

JOURNAL OF PALLIATIVE MEDICINE | Online – 14 December 2015 – Congenital anomalies account for 20% of neonatal and infant deaths in the U.S. Perinatal palliative care (PC) is a recent addition to PC and is meant to meet the needs of families who choose to continue a pregnancy affected by a life-limiting diagnosis. Perinatal PC programs are housed in academic medical centers, regional or community hospitals, local hospices, or community-based organizations. Significant differences by program setting were observed for type of fetal diagnoses seen, formal training in communicating bad news to parents, mechanisms to ensure continuity of care, and reimbursement mechanisms. One hundred percent of programs provided attention to spiritual needs and bereavement services; 70% of programs are less than 10 years old. Follow-up with parents to assess whether goals were met occurs at 43% of the perinatal PC programs. Formal measures of quality assessment were articulated in 38% of programs. This study dramatically adds to the literature available on perinatal PC program settings, types, and domains of care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0266>

Related:

- *JOURNAL OF PERINATOLOGY* | Online – 10 December 2015 – **‘Palliative care in neonatal neurology: Robust support for infants, families and clinicians.’** Infants with neurological injury and their families face unique challenges in the neonatal intensive care unit. As specialty palliative care (PC) support becomes increasingly available, we must consider how to intentionally incorporate PC principles into the care of infants with neurological injury. The authors review data regarding neonatal symptom management, prognostic uncertainty, decision making, communication and parental support for ... patients and their families. <http://www.nature.com/jp/journal/vaop/ncurrent/abs/jp2015188a.html>

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Noted in Media Watch, 30 November 2015, #438 (p.11):

- *JOURNAL OF PERINATOLOGY*, 2015;35:S19-S23. '**Recommendations for palliative and bereavement care in the NICU: A family-centered integrative approach.**' This article's defines best practice for the provision of family-centered perinatal and neonatal palliative care (PC), and provision of support to bereaved families experiencing anticipated and unanticipated life-limiting conditions or death of their infant. An overview of core concepts and values is presented, followed by intervention strategies to promote an integrated family-centered approach to palliative and bereavement care. <http://www.nature.com/jp/journal/v35/n1s/pdf/jp2015145a.pdf>

Noted in Media Watch, 26 October 2015, #433 (p.14):

- *JOURNAL OF PERINATOLOGY* | Online – 22 October 2015 – '**Primary palliative care in the delivery room: Patients' and medical personnel's perspectives.**' Most delivery room staff do not report relevant signs of distress in dying neonates and providing palliative care (PC) was not named as a relevant care related source of distress by medical personnel. Half of the study participants reported high degrees of caregiver's emotional distress in primary PC situations, identifying insecurity of how to communicate with parents and to provide emotional support as the most common source of distress. <http://www.nature.com/jp/journal/vaop/ncurrent/full/jp2015127a.html>

N.B. Selected articles on perinatal PC noted in past issues of Media Watch are listed in this issue of the weekly report.

Pre-death and post-death bereavement

Missed opportunity: Hospice care and the family

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE, 2015;11(3-4):224-243. This study explored the ways bereavement needs of caregivers, either pre-death or post-death of their spouse/partner, were addressed... Participants expressed high satisfaction with hospice care, most often noting a high satisfaction with the quality of care provided to their spouse/partner. During the pre-death phase, caregivers recalled being so focused on their spouse/partner's needs that they rarely spoke with hospice staff about their own personal needs and emotions. Participants said that bereavement counseling occurred primarily after the death of the spouse/partner, in the form of generic pamphlets or phone calls from someone they had not met during prior interactions with hospice staff. These findings suggest that caregivers' high satisfaction with hospice may be more associated with the quality of care provided to the spouse/partner than with bereavement support they received. The authors' findings illustrated a potential missed opportunity for hospices to address the family-oriented goals that are commonly put forward in hospice mission statements. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2015.1108896>

Hospice use, hospitalization, and Medicare spending at the end of life

JOURNALS OF GERONTOLOGY | Online – 11 December 2015 – Prior studies associate hospice use with reduced hospitalization and spending at the end of life based on all Medicare hospice beneficiaries. In this study, the authors examine the impact of different lengths of hospice care and nursing home residency on hospital use and spending prior to death across 5 disease groups. They compared inpatient hospital days and Medicare spending during the last 6 months of life using hospice versus propensity matched non-hospice beneficiaries who died in 2010, were enrolled in fee for service Medicare throughout the last 2 years of life, and were in at least 1 of 5 disease groups. Comparisons were based on length of hospice use and whether the decedent was in a nursing home during the seventh month prior to death. Hospice use over 2 weeks was associated with decreased hospital days (1-5 days overall, with greater decreases for longer hospice use) for all beneficiaries; spending was \$900-\$5,000 less for hospice use of 31-90 days for most beneficiaries not in nursing homes, except beneficiaries with Alzheimer's. Overall spending decreased with hospice use for beneficiaries in nursing homes with lung cancer only, with a \$3,500 reduction. The Medicare hospice benefit is associated with reduced hospital care at the end of life

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and reduced Medicare expenditures for most enrollees. Policies that encourage timely initiation of hospice and discourage extremely short stays could increase these successes while maintaining program goals. <http://psychogerontology.oxfordjournals.org/content/early/2015/12/10/geronb.qbv109.abstract>

Noted in Media Watch, 19 October 2015, #432 (p.12):

- *AMERICAN JOURNAL OF PUBLIC HEALTH* | Online – 15 October 2015 – ‘**The myth regarding the high cost of end-of-life care.**’ The authors conducted an analysis for the Institute of Medicine Committee on Approaching Death using existing national data sets, peer-reviewed literature, and published reports. They estimated that in 2011, among those with the highest costs, only 11% were in their last year of life, and approximately 13% of the \$1.6 trillion spent on personal health care costs in the U.S. was devoted to care of individuals in their last year of life. Public health interventions to reduce health care costs should target those with long-term chronic conditions and functional limitations. <http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2015.302889>

“It is not the fading candle that one expects”

General practitioners’ perspectives on life-preserving versus “letting go” decision-making in end-of-life home care

SCANDINAVIAN JOURNAL OF PRIMARY HEALTH CARE | Online – 10 December 2015 – Many general practitioners (GPs) are willing to provide end-of-life home care for their patients. Nearly all GPs [i.e., study participants] adopted a palliative approach and an accepting attitude towards death. The erratic course of terminal illness can challenge this approach. Disruptive medical events threaten the prospect of a peaceful end-phase and death at home and force the GP either to maintain the patient’s (quality of) life for the time being or to recognize the event as a step to life closure and “letting the patient go.” Making the “right” decision was very difficult. Influencing factors included: the nature and time of the crisis, a patient’s clinical condition at the event itself, a GP’s level of determination in deciding and negotiating “letting go,” and the patient’s/family’s wishes and preparedness regarding this death. Hospitalization was often a way out. GPs regard alternation between palliation and life-preservation as part of palliative care. They feel uncertain about their mandate in deciding and negotiating the final step to life closure. A shortage of knowledge of (acute) palliative medicine as one cause of difficulties in letting-go decisions may be underestimated. Sharing all these professional responsibilities with the specialist palliative home care teams would lighten a GP’s burden considerably. <http://www.tandfonline.com/doi/pdf/10.3109/02813432.2015.1118837>

N.B. Click on PDF icon to access article.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CANADIAN FAMILY PHYSICIAN*, 2015;61(12):1039-1040. ‘**Physician-assisted suicide is not a failure of palliative care.**’ Clearly, the divide about the legalization of physician assisted suicide (PAS) in Canada stems from conflict between our values and principles. Palliative care (PC) maintains good life for seriously ill patients for as long as possible. PC should not shoulder the burden of the disagreement, as it distorts the image of PC. Assigning unrealistic expectations and goals to PC teams – such as changing patients’ values – will set PC up for failure, and undermining PC will affect all vulnerable, seriously ill patients. PC is distinct from PAS and should not be part of the debate. <http://www.cfp.ca/content/61/12/1039.full>
- *UNIVERSITY OF TORONTO NEWS* | Online – Accessed 18 December 2015 – ‘**University of Toronto experts offer recommendations on physician-assisted dying.**’ Scholars from the University of Toronto Joint Centre for Bioethics have been actively engaged in developing and informing the policy and practice of physician-assisted dying (PAD). “We want to avoid a patchwork of approaches and develop aligned policies where Canadians know what to expect if they choose to request a physician-assisted death, regardless of where they live,” said Professor Jennifer Gibson, director of the Joint

Cont.

Centre for Bioethics (JCB)... Two reports published this week on PAD emphasize a collaborative, equitable approach that is part of a continuum of end-of-life care options, said Gibson, who co-chairs the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying. The group's final report¹ ... covers issues such as eligibility criteria, protection of vulnerable people, the role of conscientiously objecting health care providers, and the role of health institutions, professional regulatory bodies, and governments in providing access to PAD. Earlier this year, Gibson commissioned a JCB task force on physician-assisted death ... chaired by Philip Hébert, an emeritus professor of family and community medicine at the University of Toronto... "PAD should be considered as a last resort when other, less ethically challenging, alternatives have been exhausted, failed, or are considered unsatisfactory by the individual," the JCB task force wrote in its report...² The JCB task force strongly recommended that the introduction of PAD begin cautiously, with a robust process that promotes equitable access to PAD as one of a comprehensive range of alternatives for responding to suffering and providing end-of-life care. <http://www.news.utoronto.ca/u-t-experts-offer-recommendations-physician-assisted-dying>

1. 'Provincial-Territorial Expert Advisory Group on Physician Assisted Dying: Report,' November 2015. file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/9T1OFYF5/eagreport_20151214_en.pdf
2. 'After Carter v. Canada: Physician Assisted Death in Canada: Report and Recommendations,' Task Force on Physician Assisted Death, University of Toronto Joint Centre for Bioethics, 14 December 2015. <http://jcb.utoronto.ca/docs/JCB-PAD-TaskForce-Report-2015.pdf>

Media Watch: Online



Updated 12.21.2015

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/publications/newsletter/2015/12/media-watch/>

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

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

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

Asia

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

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

Australia

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

Europe

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

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

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

Worth Repeating

Palliative care: Benefits, barriers, and best practices

AMERICAN FAMILY PHYSICIAN, 2013;88(12): 807-813. To achieve the goal of improved hospice utilization when appropriate, some guidelines recommend that palliative care (PC) be incorporated into standard-of-care treatment approaches. One validated model that has been proven effective in patients with terminal illness includes the following: 1) Stating the prognosis at the first visit; 2) Appointing someone in the physician's office to ensure advance directives are discussed; 3) Scheduling a hospice information visit within the first three visits; and, 4) Offering to discuss the patient's prognosis, coping strategies, and goals of care at each transition. Physicians should contextualize decisions around goals of care, which preserves hope and optimism, but re-orient treatment toward appropriate aims. PC should be part of a broader continuum of care, thereby avoiding abrupt changes in the medical course. Family physicians are well-positioned to discuss advance care planning during routine office visits; several increasingly nuanced approaches are available to facilitate this discussion. Family physicians should be familiar with disease trajectories of common chronic illnesses, as well as tools that aid in prognostication. There are several validated tools that rely on performance status in conjunction with other clinical indicators (e.g., Palliative Prognostic Score, Flacker Mortality Score), as well as disease-specific tools (e.g., Model for End-Stage Liver Disease, Charlson Comorbidity Index for End-stage Renal Disease). The Patient-Reported Outcome Mortality Prediction Tool has had promising results in predicting six-month mortality in older adults, but still requires

validation for routine clinical use. Institutions should also consider implementing protocols that trigger hospice referrals based on specific clinical features (e.g., repeated or lengthy hospitalization, decline in cognitive or functional status, unacceptable pain, emotional distress), and PC utilization should be a key quality measure. Physician and nursing education must continue to incorporate these elements in clinical training. <http://www.aafp.org/afp/2013/1215/p807.html>

Extract from *American Family Physician* article

Several factors may account for the underutilization of hospice care, including confusion about terminology, misperception about its intent and scope, concerns about cost and insurance coverage, and potential mistrust because of perceived economic motives. A lack of physician comfort with end-of-life conversations, including the fear of depriving patients of hope, can also create a barrier to hospice referrals. Uncertainty about prognosis poses an additional challenge for physicians. Studies show that although the physician-patient relationship provides a meaningful context for addressing end-of-life issues, the degree of uncertainty about prognosis directly correlates with the longevity of this relationship. Insufficient training for physicians and nurses, including a lack of familiarity with various prognostic tools, may also have a role. A more subtle barrier surrounds the psychology of decision making. Patients tend to be overly optimistic, believing that prescribed treatments will cure even incurable diseases. For physicians, the fear of causing harm by failing to do something may overshadow the fear of actively doing something harmful (i.e., therapeutic optimism).

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