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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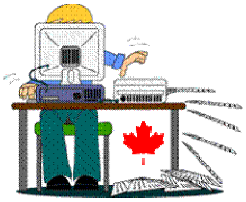

Compiled & Annotated by Barry R. Ashpole

Drug administration and storage: Scroll down to Specialist Publications and 'Family caregivers' pain management in end-of-life care: A systematic review (p.7), in *American Journal of Hospice & Palliative Medicine*.

Canada

Health advocates ask federal government to earmark money for palliative care

CANADIAN PRESS | Online – 16 March 2016 – The federal government needs to ensure there is money for palliative care (PC) in the budget next week as part of a down payment on a much larger repair project, health advocates say. The Canadian Cancer Society said the Liberal government needs to urgently address the glaring holes in end-of-life care. The debate following the Supreme Court of Canada's decision on assisted death has shown people often fall through the cracks of the health care system and improvements are needed to address the patchwork of care available, said Gabriel Miller, the society's public issues director. During the election campaign, the Liberals promised to spend $3-billion over the next four years to improve access to home care, including family and PC. Miller said the cancer society expects to see the government follow through on this investment, but he warned money cannot be used just to camouflage the biggest cracks in the system. The funding needs to signal more than just temporary relief, he added. "It needs to promise permanent solutions," Miller said. "That means really beginning with a recognition of the scale of the problem, the government's responsibility to fix that problem for everyone ... and then to set really clear targets and timelines for making the change." http://goo.gl/jVfdn3

Noted in Media Watch, 18 January 2016, #445 (p.1):

- CTV NEWS | Online – 12 January 2016 – **'Canada needs to guarantee access to palliative care, report says.'** Federal and provincial governments need to guarantee access to palliative care in legislation, the Canadian Cancer Society said as it released a report on the state of end-of-life care across the country.[1] http://goo.gl/rZbmN8

  1. 'Right to Care: Palliative care for all Canadians,' Canadian Cancer Society, December 2015. http://goo.gl/f3iFEB

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.15.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 16 March 2016 – **'Doctor-assisted dying: Why religious conscience must be part of the debate.'** The competing rights of freedom of conscience, freedom of religion and access to physician-assisted death are at an impasse in Canada. When the Supreme Court last year struck down Criminal Code prohibitions on doctor-assisted death, the issue of conscience rights jumped urgently into the national discussion. A religiously informed conscience complicates things further, and thousands of health-care professionals and hundreds of religiously based health-care institutions are demanding that their Charter rights be protected. http://goo.gl/sDaHCI

- ALBERTA | *The Edmonton Journal* – 13 March 2016 – **'Alberta doctors stepping forward to offer physician-assisted death.'** Nearly 80 doctors have told Alberta Health Services they're willing to perform physician-assisted death, says one of the doctors given the task of deciding how to put legal changes into practice. Alberta doctors will also be able to prescribe a deadly cocktail that allows patients to drink a slurry on their own, Dr. James Silvius, medical director of community, seniors, addiction and mental health for Alberta Health Services [recently] told doctors... Regulators have been preparing for the impending legalization of physician-assisted dying in Canada... Alberta patients who wish to die with a doctor's help can now apply to the Court of Queen's Bench... http://goo.gl/8afiV2

Specialist Publications

'Judge's ruling offers guidance on tough topic' (p.14), in *The Lawyers Weekly*.

'Constructing physician-assisted dying: The politics of evidence from permissive jurisdictions in *Carter v. Canada*' (p.14), in *Mortality.*

U.S.A.

After a death, some people go through prolonged suffering called complicated grief

PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 15 March 2016 – As awful as it is to lose someone we love, the vast majority of us will begin to reach some level of acceptance about six months after a death, and will begin to take a renewed interest in life within the first year to 18 months. But an estimated 7-10% of people will be caught in a more lasting pain known as complicated or prolonged grief, experts say. That seems like a modest share, but since 2.5 million people die in the U.S. each year, and each death strongly affects two to three people close to that person, that means nearly 525,000 people annually will be susceptible to prolonged grief. For certain kinds of deaths, the proportion of people who will struggle with their grief is much larger. "If you look at someone who lost a romantic partner, the risk of complicated grief is double the normal rate," says Katherine Shear, of the Center for Complicated Grief, Columbia University in New York. "If you lose a child who is a young adult, the risk is much higher." http://goo.gl/ifzdIE

Noted in Media Watch, 23 February 2015, #398 (p.3):

- *THE NEW YORK TIMES* | Online – 16 February 2015 – **'When grief won't relent.'** Most often, within six months of a death, survivors adjust and are more or less able to resume usual activities, experience joy, and remember their loved ones without intense pain. But sometimes, even when the loss is neither sudden nor unexpected survivors close to the deceased can experience extremely disruptive grief reactions that persist far longer. In a recently published report Dr. Katherine Shear presents a composite portrait of what is known as complicated grief.[1] http://goo.gl/4xXSZs

1. 'Complicated grief,' *The New England Journal of Medicine*, 2015;372(2):153-160. http://goo.gl/HT35IP

Centers for Disease Control & Prevention issues guidelines to limit opioid painkiller prescriptions

THE WALL STREET JOURNAL | Online – 15 March 2016 – The Centers for Disease Control & Prevention (CDC) has released long-awaited guidelines ... to limit prescribing of opioid painkillers, the overuse of which has contributed to a pervasive and deadly epidemic in the U.S...[1] The guidelines, which are voluntary, urge primary care clinicians – doctors, physician assistants and nurse practitioners – to offer patients alternative treatments for chronic pain ... to prescribe the lowest effective dosage possible to patients who do need opioid drugs, and monitor the patient carefully, because the drugs are highly addictive. The CDC also recommends limiting opioid prescriptions for patients suffering short-term, acute pain to three days or less in most conditions, and says that more than seven days' worth of opioid drugs "will rarely be needed." http://goo.gl/1qgCGT

Extract from *The Wall Street Journal* article

The guidelines apply to primary care clinicians treating patients for certain types of chronic pain, but not for patients in cancer treatment, palliative or end-of-life care.

1. 'CDC Guideline for Prescribing Opioids for Chronic Pain – U.S., 2016,' *Morbidity & Mortality Weekly Report*, 15 March 2016, Centers for Disease Control & Prevention. http://goo.gl/Ng6PZ5

Most home health care agencies providing average care, new data show

CONNECTICUT | *The Hartford-Courant* – 14 March 2016 – Two-thirds of Connecticut's 99 licensed home health-care agencies provide average or above-average care, and 19 were rated below average, according to new Medicare five-star rating data.[1] Just one agency ... received the highest rating of five stars; three agencies ... received 4.5 stars; and eight received four stars. Nationally, as in Connecticut, a majority of the agencies fall in the middle, with a three or 3.5 star rating, the data ... show. Of the 12,201 home-care agencies rated nationally, only 2,512 received five stars. The five-star rating system, unveiled last summer, is based on nine of 29 quality measures, including starting care in a timely manner, educating patients and caregivers about medications, and patient outcomes such as improved mobility in walking, getting in and out of bed, bathing, and no hospital readmission. http://goo.gl/5g7DzY

1. 'Home Health Compare data,' Medicare, March 2016. https://goo.gl/vjxLRT

Media Watch: Back Issues – http://goo.gl/frPgZ5

GLOBAL PALLIATIVE CARE NEWS ARCHIVE

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 452: Dying better, even if it means sooner

Download the complete issue (PDF 275 KB)

U.S. REPORT & WORLDS NEWS | *Online – 29 February 2016* | Defying and delaying death often remains the focus of many care providers even when patients reach their 80s, 90s and 100s. These individual decisions add up to the single greatest expenditure in the national health system: care in the last 12 months of life accounts for over 25% of total expenditures for both Medicare and Medicaid. **read more...**

Media Watch Archives

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

What '60 Minutes' didn't say about why "death with dignity" is so hard

FORBES | Online – 13 March 2016 – Here are some of the major impediments to improving end-of-life care in this country: Everyone is so overwhelmed with decisions during medical crises they often make the wrong ones. A 2015 study[1] ... revealed that doctors working in the intensive care unit of an academic medical center made a staggering 102 decisions per day, which averaged out to nine decisions per patient. Rightly so, these researchers and others have questioned whether such "decision fatigue" can lead to hastily made choices that patients regret later. And studies have shown that even when patients are encouraged to complete advance directives (AD), they may not express their true wishes. A 2013 study[2] ... involved 132 seriously ill patients who were randomly assigned to complete one of three AD. Most patients preferred comfort-oriented care rather than radical life-extending measures. But when patients were handed an AD with "life extension" presented as the default choice (which it is when patients don't express their desires), only 43% rejected that choice in favor of comfort-oriented care – showing just how likely people are to accept the status quo rather than speak up for what they want. Doctors often opt to sustain life even when patients don't want that. Even in the ideal scenario of everyone having an AD, there's no guarantee patients' wishes will be honored. For example, one study published in 2015[3] ... found that almost one-quarter of patients admitted to intensive care units with do-not-resuscitate orders received CPR. Med schools spend precious little time teaching doctors how to help their patients make end-of-life decisions. Palliative care became a defined medical specialty about 20 years ago and there are now hundreds of physicians who specialize in providing appropriate care at the end of life. But not every physician who treats cancer and other grave illnesses has such advance training. The average total hours of instruction in death and dying provided by American med schools is just 17 hours over the entire four years of instruction.[4] http://goo.gl/DlBqfP

DNR confusion poses a "public safety concern"

MASSACHUSETTS | *The Boston Herald* – 13 March 2016 – Confusion over living wills and Do Not Resuscitate (DNR) orders among doctors, nurses and paramedics has created a national public safety risk, a top medical researcher says. The warning follows a *Herald* report on what one hospital executive called a "misunderstanding" after an elderly man was labeled as DNR shortly before he died at Melrose-Wakefield Hospital. "This is a nationwide, public safety concern," said Dr. Ferdinando L. Mirarchi, emergency medicine director at the University of Pittsburgh Medical Center Hamot [Pennsylvania]. "My research today shows that essentially the documents are misunderstood and they're misunderstood on a nationwide scale." Dr. Gina Jervey Mohr, palliative medicine director at Loma Linda University Health [California], said health professionals often assume DNR orders end treatment. http://goo.gl/7cQnYY

N.B. The CBS News program '60 Minutes' broadcast 'Should the terminally ill control how they die?' 13 March 2016. http://goo.gl/dS0pO5

1. 'An observational study of decision making by medical intensivists,' *Critical Care Medicine*, 2015;43(8):1660-1668. http://goo.gl/199TMC
2. 'Default options in advance directives influence how patients set goals for end-of-life care,' *Health Affairs*, 2013;32(2):408-417. [Noted in Media Watch, 11 February 2013, #292 (p.9)] http://goo.gl/cz5DCq
3. 'Variability among U.S. intensive care units in managing the care of patients admitted with pre-existing limits on life-sustaining therapies,' *JAMA Internal Medicine*, 30 March 2015. [Noted in Media Watch, 6 April 2015, #404 (p.7)] http://goo.gl/roXQOv
4. 'Managing end-of-life uncertainty: Applying problematic integration theory to spousal communication about death and dying,' *American Journal of Hospice & Palliative Medicine*, 18 September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.9)] http://goo.gl/hJxf1P

Cont.

Related

- *USA TODAY* | Online – 19 March 2016 – **'Electronic records and end-of-life plans.'** In a perfect world, patients with advance directives would be confident that their doctors and nurses – no matter where they receive care – could know in a split second their end-of-life wishes. But this ideal is still in the distance. Patients' documents often go missing in maze-like files or are rendered unreadable by incompatible software. And this risk continues even as health systems and physician practices adopt new electronic health records. So advocates and policymakers are pushing for a fix. The problem isn't new, experts noted. Advance directives were lost during the era of paper records, too. But, so far, digital efforts have fallen short. http://goo.gl/ylN5IQ

- *USA TODAY* | Online – 12 March 2016 – **'Doctors ponder delicate talks as Medicare pays for end-of-life counsel.'** Physicians can now bill Medicare $86 for an office-based, end-of-life counseling session with a patient for as long as 30 minutes. Medicare has set no rules on what doctors must discuss during those sessions. Patients can seek guidance on completing advance directives stating if or when they want life support measures such as ventilators and feeding tubes, and how to appoint a family member or friend to make medical decisions on their behalf if they cannot, for instance. The new policy reflects Americans' growing interest in planning the last stage of their lives when they may be unable to make their wishes known. In 2014, the Institute of Medicine, an influential panel of experts, found that the nation's health system was not adequately dealing with end-of-life care, and among its recommendations was that insurers pay providers for advanced-care planning discussions.[1] Last September, a Kaiser Family Foundation poll found 89% of the public said that doctors should discuss end-of-life care issues with their patients, though just 17% of Americans – and 34% of people 75 and older – said that they have had such conversations.[2] http://goo.gl/Bqrbgq

  1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] http://goo.gl/6Q5VNY

  2. 'Poll finds overwhelming support for Medicare paying for end-of-life talks,' *Kaiser Health News*, 30 September 2015. [Noted in Media Watch, 5 October 2015, #430 (p.3)] http://goo.gl/RWZLhu

International

End-of-life care in Scotland

Glasgow project to become Scotland-wide as part of Scotland's new cancer strategy

U.K. (Scotland) | *The Evening Times* (Glasgow) – 15 March 2016 – The Scottish Government has pledged £9 million to set up a cancer service similar to one pioneered in Glasgow. A £100 million strategy setting out services to provide cancer care in Scotland over the next five to 10 years was announced ... by the Health Secretary.[1] The plan ... contains more than 50 actions to tackle the disease by improving prevention, detection, diagnosis, treatment and after care. Among them is a scheme to ensure better support for people with cancer and their families, modelled on a Macmillan Cancer Support project trialled in Glasgow... [and] ... includes £50 million for radiotherapy equipment and to support recruitment and training, an additional £10 million to support swift access to diagnostics for people with suspected cancer, and £5 million to support waiting times performance. Also covered is ... £3.5 million to drive improvements across the palliative care sector. http://goo.gl/yQpeMh

Extract from 'The Beating Cancer: Ambition and Action'

All health and care workers require an appropriate level of knowledge and skill in palliative and end of life care. Holistic high quality care must be delivered for everyone in accordance with the appropriate legal, professional, clinical and care standards.

1. 'The Beating Cancer: Ambition and Action' The Scottish Government, March 2016. http://goo.gl/eeyujw

Cont.

Selected articles on end-of-life care in Scotland

- U.K. (Scotland) | Scottish Public Health Network – Accessed 3 March 2016 – **'Palliative and end-of-life care in Scotland: The rationale for a public health approach.'** The report aims to examine the rationale for applying a public health approach to palliative and end-of-life care, and to explore where and how public health approaches could be applied to support local service planning and delivery. The report is accompanied by 5 briefing papers and includes 17 recommendations. [Noted in Media Watch, 7 March 2016, #452 (p.6)] http://goo.gl/FeVDfk

- U.K. (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 strategy backed by a £3.5 million investment...[1] [Noted in Media Watch, 21 December 2015, #441 (p.8)] http://goo.gl/nqudyp

    1. 'Strategic Framework for Action on Palliative and End-of-Life Care,' Scottish Government, December 2015. http://goo.gl/CKePjU

- U.K. (Scotland) | *The Courier* (Dundee) – 15 September 2015 – **'Report says 10,000 people miss out on palliative care before dying.'** More than 10,000 Scots who could benefit from palliative care towards the end of their life die without receiving it, a new report has suggested.[1] Professor David Clark, of the End-of-Life Studies Group at Glasgow University, said an estimated 40,000 people in Scotland could benefit from the specialist form of care. [Noted in Media Watch, 21 September 2015, #428 (p.6)] http://goo.gl/4JWxaz

    1. 'International comparisons in palliative care provision: What can the indicators tell us?' Health & Sport Committee, September 2015. http://goo.gl/KhqtqU

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

Doctors may treat dying patients for too long, finds British Medical Association report

U.K. | *The Guardian* – 14 March 2016 – Some doctors go on treating dying patients beyond the point at which it provides benefit because of pressure from relatives or a fear of perceived failure, a report by the British Medical Association into end-of-life care (EOLC) has concluded.[1] People nearing the end of their lives should only receive medical intervention if it is "appropriate and proportionate," according to the [Association's] inquiry, which also criticised the National Health Service (NHS) for not consistently delivering care to dying patients across the country. It urges Britain's 250,000 doctors to be guided by their clinical judgment about a patient's closeness to death and resist "pressure" from the person or their family to continue treatment that would bring no benefit. But it also advises medics not to take decisions that would leave patients feeling they have been "abandoned or denied treatment for reversible conditions or to relieve symptoms simply because they seem to be approaching the end of their life or have a terminal condition." The report, which drew on the views of 237 doctors and 269 members of the public, calls for wide-ranging changes to how the NHS handles EOLC to ensure every patient has "a good death." It identified a series of flaws in care for those nearing the end of their lives. http://goo.gl/MDwUml

Bill calling for access to 24-hour palliative care support reaches Commons

U.K. | *The Daily Express* – 18 March 2016 – A Bill to make sure no one should experience "poor or indifferent" care when they are dying has been given the green light by the House of Lords and will be introduced to the MP in the commons. http://goo.gl/tjANzA

Specialist Publications

'The British Medical Association's guidance on conscientious objection may be contrary to human rights law' (p.11), in *Journal of Medical Ethics*

'What does "terminal sedation" mean? Results of a U.K. survey' (p.8), in *European Journal of Palliative Care.*

Cont.

1. 'End-of-life care and physician-assisted dying (Volume 3): Reflections and recommendations,' British Medical Association, March 2016. [Vols. 1 & 2 noted in Media Watch, 18 January 2016, #445 (p.4)] http://goo.gl/YZvTyq.

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

Family caregivers' pain management in end-of-life care: A systematic review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 March 2016 – Pain management was the most identified burden faced by family caregivers in end-of-life caregiving. This review identified themes similar to previous reviews on family caregivers of patients with cancer or in palliative care: inadequate knowledge and assessment skills in pain management, misunderstanding of pain medications, and poor communication with the care team. Future research should design educational programs and material for family caregivers to improve their pain management knowledge and skills, communication, and engagement in care. The scientific knowledge on this topic is scarce, and level of evidence is low; it is therefore imperative to have more exploratory studies to expand the quality and quantity of evidence and increase our understanding of family caregivers' needs and barriers to pain management based on larger and more diverse patient and caregiver samples. http://goo.gl/iE15nG

Noted in Media Watch, 29 September 2014, #377 (p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 September 2014 – **'Managing end-of-life medications at home – accounts of bereaved family carers.'** Although some support with medications is provided by GPs and nurses in the community, family carers take primary responsibility for drug administration and storage. They report anxiety about giving correct and timely dosages and concerns about keeping the patient comfortable without overdosing them or risking shortening their lives. http://goo.gl/bHWZCx

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

Restricting symptoms before and after admission to hospice

AMERICAN JOURNAL OF MEDICINE | Online – 8 March 2016 – The burden of restricting symptoms increases progressively several months before the start of hospice, peaks around the time of hospice admission, and decreases substantially after the start of hospice. The results of this ongoing cohort study, coupled with the short duration of hospice, suggest that earlier referral to hospice may help to alleviate the burden of distressing symptoms at the end-of-life. http://goo.gl/2zMsP5

Direct engagement with communities and interprofessional learning to factor culture into end-of-life health care delivery

AMERICAN JOURNAL OF PUBLIC HEALTH | Online – 17 March 2016 – Aging patients with advanced or terminal illnesses or at the end of their lives become highly vulnerable when their cultural needs – in terms of ethnic habits, religious beliefs, and language – are unmet. Cultural diversity should be taken into account during palliative care (PC) delivery (i.e., non-curative, supportive care during advanced illness or at the end of life). Providers and systems deliver disparate PC to diverse patients. The author presents two strategies to improve how culturally diverse populations are served during advanced illness: 1) health service provider assessment of local populations to understand service populations' cultural needs and guide services and policy; and, 2) Interprofessional education to improve multicultural understanding among the health care workforce. http://goo.gl/bRVIRY

Towards the end of life: An in-depth exploration of the role of Admiral Nursing in dementia care

DEMENTIA | Online – 14 March 2016 – There are approximately 150 Admiral Nurses [specialist dementia nurses] in the U.K. who work alongside other health and social care professionals to support people with dementia and their family carers. However, the stigma of the disease and the lack of recognition that dementia is a life limiting illness have led to neglect in addressing the end of life challenges. The small in-depth study reported here aimed to add to an extremely limited formal evidence base for the effectiveness of this approach and to develop a greater understanding of the range of knowledge and skills required of them in ensuring they are better able to support families in the later stages of the illness. Findings focus on the experiences of family carers, the impact of performing the Admiral Nurse role and the use of qualitative measures in this setting. http://goo.gl/jgXInv

> **N.B.** See the issues of Media Watch 14 March 2016, #453 (pp.9-10) & 15 June 2015, #414 (pp.13-14), for selected articles on end-of-life care for people living with dementia.

A gap between the intention of the Swedish law and interactions between nurses and children of patients in the field of palliative oncology – The perspective of nurses

EUROPEAN JOURNAL OF ONCOLOGY NURSING, 2016;22:23-29. Often nurses [i.e., study participants] did not see and acknowledge the children of the palliative patient. They knew that the children were there and that it was important that they were there, but they challenged the order in the working environment in relation to time-allocated tasks and working flow. In the working environment patients were prioritised over relatives. From the perspective of nurses, there is a gap between the intentions of the Swedish law and the interactions between nurses and children. http://goo.gl/4VdWVI

Are genograms useful holistic assessment tools in palliative care? A literature review

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(2):66-69. Genograms were developed as a tool to gather information about family structure and history, and were popularised by family therapists using them in clinical settings. They are increasingly used in palliative care to assess the emotional and practical support needs of patients and families. On the whole, the literature considers genograms favourably, but it does not provide much hard evidence to support their use.

THE JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE
European Journal of
Palliative Care

Access requires a subscription:
Home page: http://goo.gl/WKvCC4

What does "terminal sedation" mean? Results of a U.K. survey

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(2):84-87. An online survey about terminal sedation was undertaken in the U.K., with 514 respondents from three categories: MPs and Lords, palliative care professionals, and members of the public. Survey respondents overwhelmingly agreed that terminal sedation is different from assisted suicide or euthanasia. Asked to reflect on a hypothetical patient case, most respondents agreed that terminal sedation was justified, but diverged widely on whether or not hydration and nutrition should continue. It is important to have a clear understanding of the terminology we use and reach consensus on what terminal sedation entails, particularly in the context of a possible change in legislation.

Noted in Media Watch, 15 February 2016, #449 (p.15):

- *PLOS ONE* | Online – 12 February 2016 – '**No negative impact of palliative sedation on relatives' experience of the dying phase and their well-being after the patient's death: An observational study.**' The use of sedation does not appear to have a negative influence on bereaved persons' experience of the dying phase of their deceased relative or on their own well-being after the patient's death. http://goo.gl/6jPWXm

Cont.

Noted in Media Watch, 21 July 2014, #367 (p.13):

- *SUPPORTIVE CARE IN CANCER* | Online – 15 July 2014 – **'Making sense of continuous sedation in end-of-life care for cancer patients: An interview study with bereaved relatives in three European countries.'** While most relatives believed sedation had contributed to a "good death" for the patient, many expressed concerns. These related to anxieties about the patient's well-being, their own wellbeing, and questions about whether continuous sedation had shortened the patient's life, or whether an alternative approach would have been better. http://goo.gl/cA1cYM

Brazil: Time for palliative care in the community

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(2):94-96. In Brazil, around 180,000 people could benefit from palliative care (PC) annually, but most people do not currently get any such support. A longer life expectancy, a higher number of patients with chronic and incurable diseases and an increase in the incidence of cancer (with an estimated 600,000 new cases in 2016–2017) mean that we need a new way of providing end-of-life care. This will become increasingly urgent. In Brazil, palliative care integrated into the work of primary care teams is the best solution to give everyone reliable access to PC.

Noted in Media Watch, 12 May 2014, #357 (p.8):

- **'Structuring a palliative care service in Brazil: Experience report.'** *BRAZILIAN JOURNAL OF ANESTHESIOLOGY* | Online – 29 April 2014 – One of the biggest obstacles for the viability of palliative care (PC) programs in developing countries is the lack of government commitment to the PC philosophy. In these countries, and Brazil is included, many of the difficulties in implementing PC services derive from the absence of governmental strategies and consistent national policy for pain relief... http://goo.gl/88dpY5

Noted in Media Watch, 12 July 2010, #157 (p.3):

- *ACADEMIA NACIONAL DE CUIDADOS PALIATIVOS* | Online – 10 July 2010 – **'Brazil is facing a crucial moment in its palliative care system.'** Conselho Federal de Medicina [Brazilian Federal Medicine Council] has established ... palliative care (PC) as a fundamental right for the patient and an obligation for the physicians. Associação Médica Brasileira [Brazilian Medical Association] is regulating the activity of palliative medicine and soon it will be allowed for medical colleges and major hospitals to develop internship and post-graduation programs in PC. http://goo.gl/Xg1i6r

N.B. Brazil was ranked 42nd 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://goo.gl/JsSbW3

A new national plan for palliative care raises high hopes in France

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(2):101-103. The big talk in palliative care (PC) at the moment is the national plan 2015-2018, the details of which were announced in December 2015... This will affect the whole of society, be it French citizens, palliative and non-palliative healthcare professionals, other professionals working in PC, informal carers, volunteers, education providers and health authorities. It could even help to bring about a shift in the way we view and deal with life-threatening illness and the end of life. The government is injecting €190 million into this plan, which focuses on: 1) Informing patients of their rights and ensuring person-centred care and decision-making; 2) Developing PC in the community, including in settings for the elderly or for people with physical or learning disabilities. It is the first time PC in the community is flagged up as a priority in a national strategy in France; 3) Addressing the disparities of access to PC services between different regions in France...; and, 4) Improving healthcare professionals' PC skills through education and clinical placements, and supporting research...

N.B. France was ranked 10th 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://goo.gl/JsSbW3

Cont.

Noted in Media Watch, 14 March 2016, #453 (p.13):

- *MÉDECINE PALLIATIVE* | Online – 12 March 2016 – **'The "palliative approach": 10 years on.'** The "palliative approach" is a concept developed in France in 2002. It has been practiced in hospitals since 2004, with the goal of giving palliative care to the maximum number of persons at the end of life who are hospitalized in acute care services. http://goo.gl/GKRmxG

The law in Ireland on decision-making

The Assisted Decision-Making (Capacity) Act 2015: What it is and why it matters

IRISH JOURNAL OF MEDICAL SCIENCE | Online – 16 March 2016 – The 2015 Act places the "will and preferences" of persons with impaired mental capacity at the heart of decision-making relating to "personal welfare" (including healthcare) and "property and affairs." Capacity is to be "construed functionally" and interventions must be "for the benefit of the relevant person." The Act outlines three levels of decision-making assistance: "decision-making assistant," "co-decision-maker" (joint decision-maker) and "decision-making representative" (substitute decision-maker). There are procedures relating to "enduring power of attorney" and "advance healthcare directives"; in the case of the latter, a "refusal of treatment" can be legally binding, while a "request for a specific treatment" must "be taken into consideration." Key challenges include the subtle decision-making required by patients, healthcare staff, Circuit Court judges and the director of the Decision Support Service; implementation of "advance healthcare directives," especially if they do not form part of a broader model of advance care planning (incorporating the flexibility required for unpredictable future circumstances); and the over-arching issue of logistics, as very many healthcare decisions are currently made in situations where the patient's capacity is impaired. A key challenge will lie in balancing the emphasis on autonomy with principles of beneficence, mutuality and care. https://goo.gl/VcC5Qy

Noted in Media Watch, 1 February 2016, #447 (p.12):

- *IRISH MEDICAL TIMES* | Online – 27 January 2016 – **'Guide on consent law due.'** In July 2015, legislative provisions relating to advance healthcare directives were incorporated into the Assisted Decision-Making (Capacity) Bill 2013. The guiding principle underpinning the advance health directive provisions is that an adult with capacity is entitled to refuse treatment, including resuscitation, for any reason. http://goo.gl/KQHnEV

Loss of dignity in end-of-life care in the emergency department: A phenomenological study with health professionals

JOURNAL OF EMERGENCY NURSING | Online – 11 March 2016 – Three themes that helped the authors understand the phenomenon of the loss of dignity in end-of-life care in the emergency department emerged: 1) "Being exposed in a cold world," with the sub-themes "improvising dying person care" and "a lack of space to care for the dying person"; 2) "Being self-critical with professional attitudes," with the subthemes "being aware of undignified actions" and "lack of a palliative culture"; and, 3) "Family obstinacy and hospital rescue," with the subthemes "making ill-advised choices" and "avoiding burden." The dignity of people who are taken to the emergency department at the end of their life could be undermined by architectural and organizational characteristics, professionals' attitudes, and decisions made by family members. http://goo.gl/Ua2Mqn

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 14 March 2016 – **'Palliative care education in emergency medicine residency training: A survey of program directors, associate program directors, and assistant program directors.'** There are specific barriers and opportunities for palliative care (PC) competency training and gaps in resident skill level. There are discrepancies in competency importance and residency skill in the management of the dying child, non-beneficial interventions, and ethical and legal issues that could be a focus for educational interventions in PC competency training in EM residencies. http://goo.gl/GMStp4

The British Medical Association's guidance on conscientious objection may be contrary to human rights law

JOURNAL OF MEDICAL ETHICS | Online – 18 March 2016 – It is argued that the current policy of the British Medical Association (BMA) on conscientious objection is not aligned with recent human rights developments. These grant a right to conscientious objection to doctors in many more circumstances than the very few recognised by the BMA. However, this wide-ranging right may be overridden if the refusal to accommodate the conscientious objection is proportionate. It is shown that it is very likely that it is lawful to refuse to accommodate conscientious objections that would result in discrimination of protected groups. It is still uncertain, however, in what particular circumstances the objection may be lawfully refused, if it poses risks to the health and safety of patients. The BMA's policy has not caught up with these human rights developments and ought to be changed. http://goo.gl/jeUl34

Lifting shadows off the end-of-life care: Hopes and beliefs on video decision support tools for advance care planning

KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE, 2016;19(1):1-4. As advance care planning is taking center stage in the field of end-of-life care, various tools have been developed to aid in the often emotional and difficult decision-making process. Video decision support tools are one of the most promising means of assistance, of which the *modus operandi* is to provide more comprehensive and precise information of medical procedures to patients and their families, allowing them to make better informed decisions. Despite such value, some are concerned about its potential negative impact. For example, video footages of some procedures may be shocking and unpalatable to non-medical professionals, and patients and families may refuse the procedures. One approach to soften the sometimes unpleasant visual of medical procedures is to show less aggressive or more relaxing scenes. Yet another potential issue is that the objectivity of video decision support tools might be vulnerable to the very stakeholders who were involved in the development. Some might argue that having multiple stakeholders may function as checks and balances and provide collective wisdom, but we should provide more systematic guarantee on the objectivity of the visual decision aids. Because the decision of the modality of an individual's death is the last and most significant choice in one's life, no party should exert their influence on such a delicate decision. With carefully designed video decision support tools, our patients will live the last moments of their lives with dignity, as they deserve. http://goo.gl/jgkCqz

한국 호스피스 · 완화의료학회지

THE KOREAN JOURNAL OF
HOSPICE AND PALLIATIVE CARE

The focus of this issue of the *Korean Journal of Hospice & Palliative Care* is end-of-life care. Contents page (English language edition): http://goo.gl/4MV3Bb

N.B. South Korea was ranked 18th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. Commissioned by the Lien Foundation of Singapore [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://goo.gl/bT3PV5

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 arch 2016 – '**Determining consistency of surrogate decisions and end-of-life care received with patient goals-of-care preferences.**' Twenty-four patients (53.3%) received care consistent with written preferences and 11 (24.4%) inconsistent with written preferences. The remaining 10 patients (22.2%) died suddenly with no opportunity for treatment decision making. Eleven (24.4%) were able to participate in decision making with their surrogates; of those, 9 (81.8%) received care consistent with their expressed preferences. Simply comparing documented preferences for end-of-life care and medical records of care delivered does not adequately reflect the process of advance care planning and treatment decision making at the end of life. http://goo.gl/p46jh4

Cont.

- *MEDICAL DECISION MAKING* | Online – 14 March 2016 – **'Extent and predictors of decision regret about health care decisions: A systematic review.'** People often face difficult decisions about their health and may later regret the choice that they made. However, little is known about the extent of decision regret in health care or its predictors. The extent of decision regret as assessed with the Decision Regret Scale in non-hypothetical health decisions was often low but reached high levels for some decisions. Several risk factors related to the decision-making process significantly predicted decision regret. http://goo.gl/GpZL4w

End-of-life care in Slovenia

Criminal law dilemmas in withholding and withdrawal of intensive care

MEDICINE, LAW & SOCIETY, 2016;9(1):21-29. Regarding the question under which conditions a physician in Slovenia is allowed to omit life-prolonging medical treatment of dying patients, the main legal source is the Patient Rights Act, adopted in Slovenia in 2008 (parallel to Criminal Code of Slovenia). Under this law, there are two possible circumstances in deciding about life-prolonging medical treatment regarding dying patients: a) on the basis of the so-called patient's testament in the sense of Article 34 of the Patient Rights Act; and, b) without any known patient's testament in the sense of Article 34 of the Patient Rights Act. Such decisions can also be contrary to a decisive wish of relatives of the dying patient to prolong the patient's life under all circumstances. If this decision is reached with full respect of the Patient Rights Act as well as the rules of medical science, omitting life prolonging medical treatment cannot be unlawful in the sense of medical criminal law. http://goo.gl/bGEviY

Noted in Media Watch, 18 November 2013, #332 (p.14):

- *ZDRAVNIŠKI VESTNIK* (Slovenian Medical Journal), 2013;82(9):589-601. **'End-of-life ethical dilemmas in intensive care unit.'** The decision regarding continuing or stopping treatment should be based on careful evaluation of the balance between its expected efficiency and benefits on the one hand and the burden imposed upon the patient on the other. If the burden clearly exceeds the expected benefits, the ethically sound decision is to terminate such treatment. http://goo.gl/VMy241

How we die: A view from palliative care

QUT LAW REVIEW, 2016;16(1):5-21. There is an ongoing global conversation about dying, particularly with regard to treatment abatement decisions, causation and responsibility for death, and relief of physical and existential suffering. There is rising international support for assisted dying. People now tend to die slowly in old age, as a result of multiple chronic illnesses, with more medical decision points and impaired cognitive capacity. This paper describes the dying process from the standpoint of palliative medicine and argues for an improved common recognition of the process of dying, in its contemporary spiritual and social contexts, by the public, medicine, ethics, public policy and the law. https://goo.gl/4O1wno

QUT | QUT Law Review

The focus of this issue of the Queensland University of Technology's *QUT Law Review* is end of life. The issue includes seven articles which span the four themes of the 2014 International Conference on End of Life: 1) Withholding and withdrawing potentially life-sustaining treatment; 2) Euthanasia and assisted suicide; 3) Palliative care and terminal sedation; and, 4) Determination of death and organ donation. Contents Page: https://goo.gl/RgPmog

Media Watch: Palliative Care Network-e Website

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. http://goo.gl/8JyLmE

Themes and variations: An exploratory international investigation into resuscitation decision-making

RESUSCITATION | Online – 11 March 2016 – International variation in clinicians' perception of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision-making and implementation, and the factors influencing such variation, has not previously been explored. All continents were represented: 88% of respondents reported a method for implementing DNACPR decisions, 90% of which discussed resuscitation wishes with patient at least half of the time; 94% of respondents thought that national guidance for DNACPR order implementation should exist, with 53% of countries surveyed reporting existence of such guidance. Cultural attitudes towards death, medical education and culture, health economics, and the societal role of family were commonly identified as factors influencing perception of DNACPR decisions. http://goo.gl/sNCM0G

Noted in Media Watch, 25 January 2016, #446 (p.16):

- *RESUSCITATION* | Online – 14 January 2016 – **'A survey of key opinion leaders on ethical resuscitation practices in 31 European Countries.'** The authors report the responses to a questionnaire covering four domains of resuscitation: 1) Approaches to end-of-life care and family presence during CPR; 2) Determinants of access to best resuscitation and post-resuscitation care; 3) Diagnosis of death and organ donation; and, 4) Emergency care organisation. http://goo.gl/me0mUy

Noted in Media Watch, 19 January 2015, #393 (p.9):

- *BMJ OPEN* | Online – 13 January 2015 – **'Variation in local trust Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policies: A review of 48 English healthcare trusts.'** There was variation in terminology (85% described documents as policies, 6% procedures, and 8% guidelines). Only one quarter of Trusts used the recommended Resuscitation Council record form (or a modification of the form). There was variation in the terminology used, which included DNAR (Do Not Attempt Resuscitation), DNACPR (Do Not Attempt CPR), CPR, and AND (Allow Natural Death). http://goo.gl/cxZMNM

- *JOURNAL OF MEDICAL ETHICS* | Online – 17 March 2016 – **'In what circumstances will a neon'atologist decide a patient is not a resuscitation candidate?'** A majority of neonatologists [i.e., survey respondents] believed unilateral DNAR decisions are ethically permissible if survival is felt to be impossible, but not permissible based solely on poor neurological prognosis. This has significant implications for clinical care. http://goo.gl/rxWvzb

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *AMERICAN JOURNAL OF MEDICINE* | Online – 15 March 2016 – **'Turning points in the conception and regulation of physician-assisted dying in The Netherlands.'** The Netherlands have a long history of tolerating, legislating, and regulating physician-assisted dying. It is safe to say that legalization has contributed to a normalization of physician-assisted dying and has led, due to its unavoidably flexible and ambiguous nature, to an expansion of its practice. This history may be informative for countries that are currently making decisions at an earlier turning point. http://goo.gl/w2eyZ7

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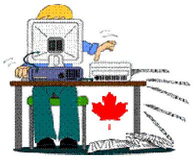

Barry R. Ashpole

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://goo.gl/5CHoAG

- *CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS*, 2016;25(2):228-238. **'Undignified arguments.'** This article provides an analysis of the current resurgence of "undignified" arguments and argues on the basis of that analysis 1) that a proper understanding of the concept of dignity shows the previous reductive arguments against dignity are partially incomplete and therefore partially misguided, and 2) that, despite dignity having meaning, the idea of an undignified death cannot carry the moral weight it is given by proponents of the legalization of physician-assisted dying. http://goo.gl/5xAo67

- *THE LAWYERS WEEKLY* (Canada) | Online – 18 March 2016 – **'Judge's ruling offers guidance on tough topic.'** The first Canadian judgment to culminate in a physician-assisted death provides help to judges and lawyers across the country on the analysis, evidence and process for Carter applications – topics on which various court protocols and attorneys general diverge. http://goo.gl/7NpMv5

- *MORTALITY* | Online – 17 March 2016 – **'Constructing physician-assisted dying: The politics of evidence from permissive jurisdictions in *Carter v. Canada*.'** The recent case of *Carter v. Canada*, which decriminalised physician-assisted dying (PAD) in Canada in 2015, provides us with an empirical opportunity to investigate how actors deployed and interpreted new knowledge. The authors found that actors [i.e., protagonists] used expert evidence from permissive jurisdictions to construct different meanings of PAD as a legalised medical practice. The opponents constructed PAD as a practice accessed by patients who were suicidal, performed by uncaring physicians unskilled in end-of-life care, and loosely regulated through a fallible regime. The proponents used the evidence to construct PAD as a practice borne out of a patient's rational choice, performed by caring physicians within an environment where end-of-life care had improved since legalisation, and tightly regulated through a regime where participants function as sentries overseeing each other's actions. In the final analysis, the authors argue that the proponents' success in this case contributed to the production and reproduction of a specific cultural script that renders PAD culturally appropriate. http://goo.gl/DfmDDG

Media Watch: Editorial Practice

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

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2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
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5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. 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

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/zJ7jOo

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://goo.gl/frPgZ5

PALLIATIVE CARE NETWORK COMMUNITY: http://goo.gl/8JyLmE

PALLIMED: http://goo.gl/7mrgMQ [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: HTTP://GOO.GL/JNHVMB

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://goo.gl/XrhYCH

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): http://goo.gl/AhlqvD

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: http://goo.gl/o7kN3W [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: http://goo.gl/5d1I9K

U.K. | Omega, the National Association for End-of-Life Care: http://goo.gl/UfSZtu

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