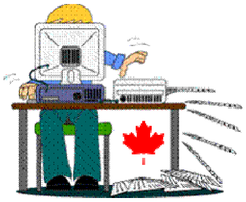
Media Watch...

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.*

29 February 2016 Edition | Issue #451



Compilation of Media Watch 2008-2016 ©

Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'How healthcare systems evaluate their advance care planning initiatives: Results from a systematic review' (p.11), in *Palliative Medicine*.

Canada

Innovative Western-led palliative care approach implemented by U.K.-based hospice

ONTARIO | *Exchange Magazine* (Waterloo) – 25 February 2016 – An innovative, new approach to delivering community-based end-of-life care (EOLC) – developed and piloted by South West Community Care Access Centre and being evaluated by [University of] Western [Ontario] researchers[1] – is now being used by a palliative care (PC) centre in the U.K. St. Luke's Hospice in Sheffield, England, is the first British PC centre participating in this pioneering international project aimed at providing greater levels of EOLC for patients in their own homes. EnComPaSS (Enhanced Community Palliative Support Services)... It is anticipated that EnComPaSS will reduce the need for hospital admissions in England by between 40-52%. The partnership was awarded £250,000 (approximately $500,000 CDN) from the National Health Services Nursing Technology Fund to develop the technology and training required to fully integrate EnComPaSS. http://goo.gl/e9UkmS

1. 'Moving towards an enhanced community palliative support service (EnComPaSS): Protocol for a mixed method study,' *BMC Palliative Care*, 30 April 2015. http://goo.gl/Pc3kV2

Switching provinces not so easy for terminally ill patients

ONTARIO | *The Globe & Mail* – 23 February 2016 – For many patients, the basic coverage paid by their former home province is usually sufficient to get them through any medical emergencies that might arise during the first three months in their new location. But it may not be enough for patients with additional needs – such as those who are terminally ill – because their former home province will not cover a lot of the "extras" such as home care and drug coverage. "We get patients who want to be near family at the end of their lives," says Dr. Darren Cargill, medical lead of a palliative care (PC) team in Windsor, Ontario. "Because of the three-month rule, we are not able to provide them with the best possible care." During the past year, Cargill and his medical colleagues have cared for three patients who returned to Ontario to die. In all three cases, the patients were admitted to a local residential hospice, even though they weren't entitled to a full range of support services, including nursing staff. "We were trying to take care of them with one arm tied behind our back." Cargill, who is the section chair on PC for the Ontario Medical Association, believes many other doctors must be grappling with the problem of patients caught in a similar position. What's needed is some kind of "compassionate clause" that would allow us to provide these patients with the appropriate care in the time they have left. http://goo.gl/zpXD2g

Home funeral workshops teach loved ones to care for corpses

MACLEAN'S MAGAZINE | Online – 21 February 2016 – It's only because Deborah Magdee happened to overhear a radio show two years ago that she left her mother's dead body at home for five days. The radio segment introduced the Vancouverite to home funerals, where family and friends assume the role of a mortician rather than relying on a morgue. Proponents say it's a cheaper, more intimate experience that can help loved ones with their grief. The more Deborah listened to how the funeral industry handled corpses, the more she wanted to explore the possibility of a home funeral. In 2013, the average cost of a funeral in Canada was between $8,000 and $10,000, according to the most recent figures from the Funeral Service Association of Canada. Deborah paid $1,266 for her mother's – something she thinks the frugal matriarch would have appreciated. http://goo.gl/MXNkUb

Noted in Media Watch, 4 May 2015, #408 (p.4):

- CBC RADIO | Day 6 (News Magazine) – 26 April 2015 – **'Death midwives help families cope with end-of-life care.'** A death midwife (or death doula, as they're sometimes called) can help create death plans, some provide spiritual care, psychological and social support, and sometimes even physical care. They can help plan home vigils and home funerals, and offer guidance with respect to what your rights and responsibilities are in caring for someone who's died. http://goo.gl/9KRA73

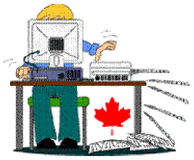
Palliative care in Newfoundland headed in right direction, says director

NEWFOUNDLAND & LABRADOR | CBC News (St. John's) – 21 February 2016 – The Newfoundland & Labrador Medical Association says the provincial government should use its fiscal crisis to design a leaner and stronger public health system including improved palliative care (PC) for an ageing population. Dr. Susan MacDonald, medical director of PC at Eastern Health, said a lot has been done to improve services and more is needed, but we're heading in the right direction. "I would say we are about 50% where we need to be," said MacDonald. "If we could design the perfect system I would be strongly advocating for education for family physicians ... and the second thing would be the community health nurses, making sure those individuals have the same opportunity for education." In 2009, a report slammed the PC system that was in place, calling it completely inadequate.[1] It found that few of the people who die in Newfoundland and Labrador have access to appropriate PC, and spend their final days in needless anguish. http://goo.gl/lOYe6W

1. 'Thousands "suffer hideously," palliative care report finds,' CBC News, 2 June 2009. [Noted in Media Watch, 8 June 2009, #100 (p.1). CBC News obtained a copy of the report, which was not publicly released. http://goo.gl/QP8xCv

Noted in Media Watch, 13 August 2012, #266 (p.6):

- *JOURNAL OF PALLIATIVE CARE*, 2012;28(2):105-112. **'Palliative and end-of-life care in Newfoundland's deaf community.'** Key research findings indicate that the deaf community has limited understanding of their options for palliative and end-of-life care (EOLC). Communication and health literacy are key barriers to accessing appropriate EOLC. Pain and symptom management, consideration of physical environments, and limited access to bereavement care are common issues faced by deaf people when caring for loved ones at the end of life. http://goo.gl/NNe38m



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

Assisted (or facilitated) death

Representative sample of recent news media coverage of the recommendations of the The Special Joint Committee on Physician-Assisted Dying:

- *THE GLOBE & MAIL* | Online – 26 February 2016 – **'Recommendation to require referrals for assisted death disappointing: Canadian Medical Association.'** A parliamentary committee's recommendation that doctors who object to assisted dying be required to at least refer patients to a willing colleague is not only disappointing, but has also led some physicians to consider leaving their practices, says the Canadian Medical Association (CMA). http://goo.gl/LnXoik

- CKNW NEWS (Vancouver BC) | Online – 25 CBC NEWS | Online – 25 February 2016 – **'Let Canadians plan ahead for doctor-assisted death, report advises.'** Canadians should have the right to make an "advance request" for doctor-assisted death after being diagnosed with certain debilitating, but not necessarily terminal, conditions, according to a special committee of MPs and senators. The advance consent provision is one of 21 recommendations made in a 70-page report tabled [in the House of Commons].[1] The report also says the right to assisted death should not be limited to physical conditions, and that Canadians with psychiatric conditions should not be excluded from doctor assistance to end suffering. The report also recommends a two-stage legislative process. The first would apply to competent adults 18 years or older to be followed by a second stage with competent mature "minors" to come in to force no later than three years later. http://goo.gl/p4oGUx

  1. 'Medical Assistance in Dying: A Patient-Centred Approach,' The Special Joint Committee on Physician-Assisted Dying. http://goo.gl/Lo7RP3

- BRITISH COLUMBIA | CBC News (Vancouver) – 25 February 2016 – **'Doctor-assisted death "not permitted" at Vancouver's Providence Health Care centres: Memo.'** A leaked memo reveals physician-assisted death is "not permitted" at a Catholic-based health provider in Vancouver, putting into question how it will adjust its policies when a recent Supreme Court of Canada ruling becomes federal legislation. Providence Health Care (PHC) operates hospitals and health services in Vancouver, including St. Paul's Hospital downtown. The internal memo ... outlines PHC policies in light of the physician-assisted death (PAD) ruling. Federal legislation is expected to come into effect in June. "PHC provides health care in conformity with the Catholic Health Alliance of Canada (CHAC) Health Ethics Guide," says the memo. "Accordingly, and at the most fundamental level, PAD contradicts the basic tenets of Catholic health care – wherein life is held to be sacred from conception to natural death – and not permitted in Catholic health care institutions such as Providence." http://goo.gl/HWHfn7

  Related

  - ONTARIO | CBC News – 27 February 2016 – **'Bruyère won't offer physician-assisted death: Memo.'** Bruyère, a publicly funded Catholic health-care provider in Ottawa that offers palliative care, will not provide physician-assisted death or refer patients to the service despite a Supreme Court ruling striking down the ban, its head says in a memo obtained by CBC News. http://goo.gl/Tnsj6G

- *THE GLOBE & MAIL* | Online – 23 February 2016 – **'Assisted dying: A Charter issue that demands a vote of conscience.'** Exploring the nebulous difference between a Charter issue and one of conscience could occupy law students indefinitely, especially because freedom of conscience is a Charter right. But apart from the fact that the Supreme Court expressly left it, within broad and undefined guidelines, largely to Parliament to decide what the legislation should be, what about MPs' Charter rights to freedom of conscience? We should keep in mind that just as respect for physicians' freedom of conscience is necessary, not only to respect them but also to protect patients and can be the last such protection against doing them harm or other serious wrongdoing, so, too, is respect for MPs' freedom of conscience necessary, not only to respect them, but also to protect Canadians and can be the last such protection against doing them harm or other serious wrongdoing. http://goo.gl/NQuyxH

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.

U.S.A.

New Jersey federal court's hospice care decision potentially expands scope of False Claims Act

NEW JERSEY | *The National Law Review* – 24 February 2016 – The ruling potentially expands the scope and reach of the False Claims Act and adds more controversy to the "implied certification" theory of claims. The ruling was issued by Chief U.S. District Court Judge Jerome Simandle in a case pending in New Jersey... Federal regulations impose strict eligibility standards for hospice care in order to receive government funds. Generally, doctors must certify that patients are terminal and within the last six months of their lives. A recent study found that a large percentage of hospice patients now spend three years and sometimes more in hospice care. This causes a huge burden on state and federal healthcare funding. http://goo.gl/0rnp8B

Specialist Publications

'U.S. physicians overwhelmingly endorse hospice as the better option for most patients at the end of life' (p.11), in *American Journal of Hospice & Palliative Medicine.*

'Palliative care in rural Minnesota: Findings from Stratis Health's Minnesota Rural Palliative Care' (p.10), in *Minnesota Medicine*.

'Misunderstood speciality: Many physicians still don't understand how palliative care works and how it differs from hospice' (p.10), in *Minnesota Medicine.*

Noted in Media Watch, 22 February 2016, #450 (p.3):

- *THE WALL STREET JOURNAL* | Online – 18 February 2016 – **'Lengthy hospice care boosts Medicare bills.'** Medicare pays hospice agencies to care for patients who are close to death. For some beneficiaries of the taxpayer-funded program, hospice has become a way of life. Between 2005 and 2013, about 107,000 patients received hospice care for an average of nearly 1,000 days spread out over four or more calendar years, according to a *Wall Street Journal* analysis of Medicare billing records. Medicare's hospice program ... is supposed to be only for patients who doctors certify are likely to die within six months, or about 180 days. http://goo.gl/uzC0sl

Choosing a hospice that fits your needs...

MICHIGAN | *Petoskey News-Review* – 23 February 2016 – Northern Michigan is mostly rural and sparsely populated. Yet, there are at least eight different hospice organizations serving Northern Michigan. They include for-profit and not-for-profit hospices – hospices affiliated with major companies outside the area, and those that are independently managed right here in our own community. The number and variety of options is a testament to how important hospice care can be to those in need. Like physicians and specialists, hospice organizations all strive to do good work, but each has its own strengths and limitations. Each follows different protocols and offers different programs; some may fit well with your family's needs, and some may not. While they all operate on the same basic premise – that hospice provides support and care for persons with life-limiting illnesses, and recognizes death as a normal part of the life cycle – their philosophies on how to carry out their work may differ vastly. http://goo.gl/WQzPbD

House passes bill that would grant terminal patients access to new drugs

OHIO | *The Columbus Dispatch* – 23 February 2016 – The Ohio House approved a "right to try" law today, which would allow terminal patients to test treatments not yet approved for general use by federal government. The program would only allow for the distribution of "investigational drugs," which means they have gone through one level of screening by the Food & Drug Administration and were found safe based on initial testing. Some additions were made to the bill since it had been introduced in October. One clause offers treatments to individuals suffering from progressive skeletal and neurological diseases, while another requires that individuals seeking treatment receive an opinion from a second physician. http://goo.gl/DSuwA7

Cont.

Related

- IDAHO | KIVI TV News (Nampa) – 23 February 2016 – **'Idaho House committee approves "Right to Try" bill.'** A House panel has approved a bill that would allow patients with terminal diseases to try drugs that have yet to obtain the Food & Drug Administration's final approval. House Bill 481 passed through the House Health & Welfare Committee in an 8-2 vote. It will now face the full House for a vote. http://goo.gl/udssvs

Noted in Media Watch, 5 October 2015, #430 (p.7):

- *ANNALS OF INTERNAL MEDICINE* | Online – 29 September 2015 – **'Right-to-try laws: Hope, hype, and unintended consequences.'** Most right-to-try laws do not set qualifications for either the health care provider making attestation of terminal illness or the physician recommending experimental treatment. Worse, the door is left open for the unscrupulous or inept to prey on desperately ill patients and their families. Further, the laws absolve companies and physicians from legal liability should be the experimental product cause harm. http://goo.gl/JWjfuy

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLORADO | *The Denver Post* – 24 February 2016 – **'End of Life Options bill pulled before Colorado House debate.'** Colorado's physician-assisted suicide bill, the proposed End of Life Options Act, faced long odds ... but it was a rare move for House Democrats to move it off the calendar before any floor debate. Democrats didn't have the votes to pass it, so the bill's sponsors chose not to put fellow legislators torn over the issue – with their own consciences, as well as their November voters – in a position to have to take a position. http://goo.gl/6d2ZCA

International

End-of-life care in England

Poor end-of-life care experienced by 48,000 people

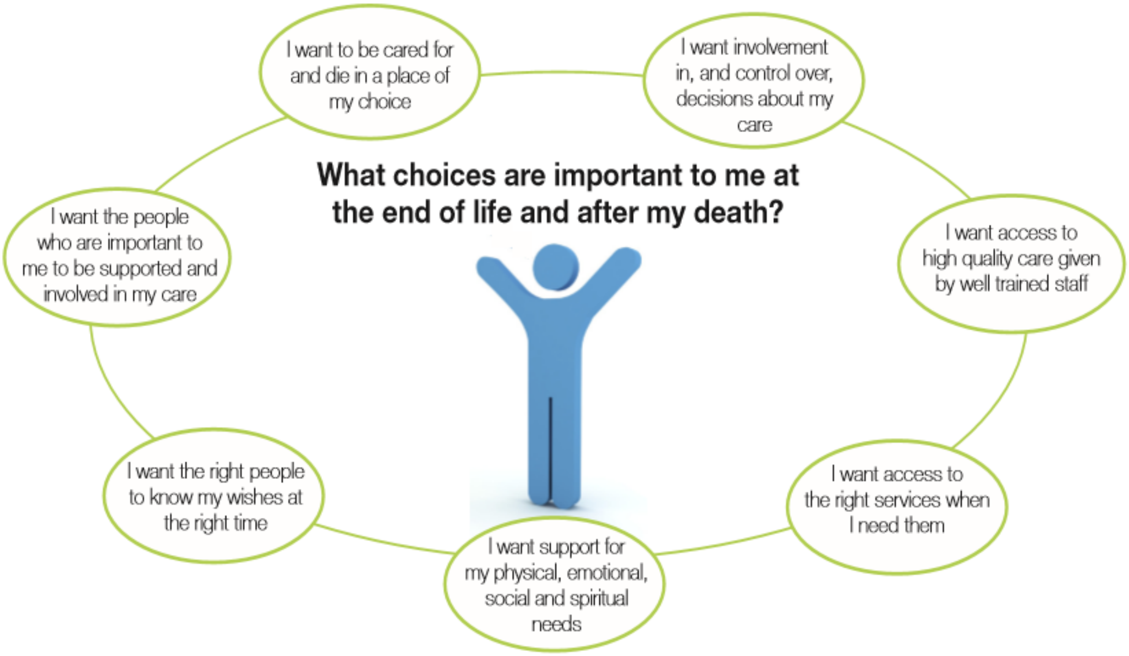
U.K. (England) | BBC News – 26 February 2016 – An estimated 48,000 people who died last year experienced poor care when dying, says a report from seven charities...[1] This is due to too many people dying in hospital, rather than at home or in other settings, it says, where they would prefer to be. The report calls on the government to set out how they are going to improve end-of-life care (EOLC). National Health Service (NHS) England said instances of poor care should be taken seriously. And it said a recent survey found three-quarters of bereaved people rated the overall quality of EOLC for their relative as "good" or "better." The report ... details the way in which dying people are currently failed by the system. It says some people are left unsupported at home at the end of their lives and many families receive no advice on how to care for their dying relatives. This can lead to people being admitted to hospital in an emergency when they are seriously ill. The report ... said this is putting extra pressure on the NHS resources – costing an average of £4,500 per person who dies in hospital and accounting for nearly three million bed days for people at the very end of their lives. http://goo.gl/kSy7NL

Specialist Publications

'Hospital at home: Home-based end-of-life care' (p.8), in *Cochrane Database Systematic Reviews.*

'Moving the integration of palliative care from idea to practice' (p.11), in *Palliative Medicine.*

Cont.



1. 'On the Brink: The Future of End of Life Care,' published by The Choice in End-of-Life Care Programme Board (Macmillan Cancer Support, Marie Curie, Cicely Saunders Institute, Hospice UK, Motor Neurone Disease Association, National Council of Palliative Care, and Sue Ryder), February 2016. https://goo.gl/KAiqDY

Elder care in the U.K.

Survey warns of care work sector crisis

U.K. | AOL.com – 22 February 2016 – Thousands of jobs that no-one wants to do, like looking after the vulnerable and elderly, could leave care work in crisis, a survey claims. Two-thirds of adults polled would shun a job as a care worker yet more than half agreed home care was essential in today's ageing society. The results indicate the care sector could face a recruitment crisis in coming years, with a potential shortfall of one million workers in the sector in the next 20 years. The YouGov poll of 2,044 people was commissioned by home care provider Home Instead Senior Care. While 53% agreed home care was essential, 68% said they would never take up such a role themselves. Just under half thought home care involves unpleasant and menial tasks, with 39% believing such workers are often treated by the care firms they work for. More than a third thought they were too old for a care worker job. http://goo.gl/jqHdMH

Media Watch: Back Issues – http://goo.gl/frPqZ5

Home > Global Palliative Care News Archive

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.
Barry R. Ashpole, Guelph, Ontario, CANADA
519.837.8936 | barryashpole@bell.net

MW 444: Prognosis, treatment benefit and goals of care: What do oncologists discuss with patients who have incurable cancer?

Download the complete issue (PDF 540 KB)

CLINICAL ONCOLOGY | *Online – 14 December 2015* | The authors describe documentation of prognosis, treatment benefit and goals of care discussions in outpatients with advanced cancer. **read more...**

Media Watch Archives

- 2014, July - December
- 2014, January - June
- 2013, July - December
- 2013, January - June
- 2012, July - December
- 2012, January - June
- 2011, July - December
- 2011, January - June
- Current

The spirit of healthcare: The National Health Service's £25 million brigade of chaplains

U.K. (England) | *The Guardian* – 22 February 2016 – There were 916 NHS chaplaincy posts in 2015, according to new data from the Health & Social Care Information Centre. The number has fallen almost 20% in the past five years, down from 1,107 in 2010. The cost to the health service is estimated to be upwards of £25 million, covering full-time and part-time positions – the equivalent of more than 1,000 junior nurses. Reflecting the rapidly changing nature of faith and belief in the U.K., National Health Service (NHS) chaplains are becoming more religiously diverse and even non-religious, with the first humanist chaplain to take a paid post beginning work this month. In the 2011 census, about a quarter of the population said they had no religion. The vast majority of chaplains are Anglicans, but others are Catholics, members of Free churches, Muslims, Jews, Sikhs, Hindus and Buddhists. Staff chaplains are supported by thousands of volunteers. Official guidelines issued by the NHS last spring defined chaplaincy as "focused on ensuring that all people, be they religious or not, have the opportunity to access pastoral, spiritual or religious support when they need it." http://goo.gl/9U9SCa

What is quality spiritual care in health care and how do you measure it?

HEALTHCARE CHAPLAINCY NETWORK | Online – 17 February 2016 – This statement provides guidance to advocacy groups, professional health care associations, health care administrators, clinical teams, researchers, government and other funders, faith communities, spiritual care professionals, and other stakeholders internationally on the indicators of quality spiritual care in health care, the metrics that indicate quality care is present and suggested evidence-based tools to measure that quality. http://goo.gl/uZELxQ

Noted in Media Watch, 27 July 2015, #420 (p.17):

- *JOURNAL FOR THE STUDY OF SPIRITUALITY*, 2015;5(1):60-69. **'Hospice chaplains: Talking about spiritual care and avoiding the modern day "inquisition."'** The paper summarizes the history of spirituality and spiritual care in English healthcare, considers the significance of Cicely Saunders's spirituality for her vision of hospice, and presents some of the findings from the author's ongoing doctoral research. http://goo.gl/vE4TMN

Noted in Media Watch, 20 July 2015, #419 (p.11):

- *JOURNAL OF HEALTH CARE CHAPLAINCY* | Online – 13 July 2015 – **'Recognizing success in the chaplain profession: Connecting perceptions with practice.'** The current investigation examines the communicative hallmarks [i.e., non-verbal vs. verbal hallmarks] of successful chaplaincy work as articulated by professional chaplains providing spiritual care at the end-of-life. http://goo.gl/Z1USCE

N.B. Selected articles on spirituality in the context of end-of-life care are noted in Media Watch of 8 June 2015, #413 (pp.10-11).

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

Is there a place for humor in hospice palliative care? Volunteers say "yes"!

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 25 February 2016 – The results [of a survey] revealed that most patients and volunteers initiated humor either "often" or "sometimes" in their interactions. Over half of the volunteers considered humor to be either "very important" or "extremely important" in their interactions with patients (42% and 13%, respectively), with the patient being the determining factor as to whether and when it is appropriate or not (i.e., volunteers take their lead from their patients). Volunteers mentioned a number of functions that humor serves within their patient interactions (e.g., to relieve tension, to foster relationships/connections, and to distract). Laughter and humor fulfills one of the main goals of hospice palliative care, namely, improving patients' overall quality of life. http://goo.gl/gr66fa

Cont.

Selected articles on humour in the context of end-of-life care

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 3 February 2014 – **'The acceptability of humor between palliative care patients and health care providers.'** A large majority of participants in this study valued humor highly both prior to (77%) and during (76%) their illness experience. Despite this valuation, the frequency of laughter in their daily lives diminished significantly as patients' illness progressed. [Noted in Media Watch, 10 February 2014, #344 (p.7)] http://goo.gl/v7GQTE
- *HEALTH EXPECTATIONS* | Online – 2 January 2012 – **'Humour in health-care interactions: A risk worth taking.'** Patients [i.e., study participants] hold a broad appreciation of humour and recognize it as being evident in subtle and nuanced forms. A chasm exists between what patients apparently want with regard to humour use in health-care interactions and what actually transpires. Initiating humour involves risk, and risk-taking requires a degree of self-esteem and confidence. [Noted in Media Watch, 9 January 2012, #235 (p.9)] http://goo.gl/vVJVoj
- *JOURNAL OF CLINICAL NURSING*, 2008;17(8):1088-1095. **'From critical care to comfort care: The sustaining value of humour.'** Studies identify situations involving serious discussion, life-threatening circumstances and high anxiety as places where humour may not be appropriate. The authors' of this article demonstrate humour is significant even where such circumstances are commonplace. Humour serves to enable co-operation, relieve tensions, develop emotional flexibility and "humanise" the health-care experience for both caregivers and recipients of care. [Noted in Media Watch, 30 April 2012, #251 (p.13, under 'Worth Repeating')] http://goo.gl/PVDVGu

Hospital at home: Home-based end-of-life care

COCHRANE DATABASE SYSTEMATIC REVIEWS | Online – 18 February 2016 – A number of countries have invested in health services to provide care at home to people with a terminal illness who wish to die at home. The preferences of the general public and people with a terminal illness seem to support this, as most people indicate that they would prefer to receive end-of-life care (EOLC) at home. The authors included four trials in their review and report that people receiving EOLC at home are more likely to die at home. It is unclear whether home-based EOLC increases or decreases the probability of being admitted to hospital. Admission to hospital while receiving home-based EOLC varied between trials. People who receive EOLC at home may be slightly more satisfied after one month and less satisfied after six months. It is unclear whether home-based EOLC reduces or increases caregiver burden. Healthcare costs are uncertain, and no data on costs to participants and their families were reported. People who receive EOLC at home are more likely to die at home. There were few data on the impact of home-based end-of-life services on family members and lay caregivers. http://goo.gl/3N0EfE

The characteristics of advanced cancer patients followed at home, but admitted to the hospital for the last days of life

INTERNAL & EMERGENCY MEDICINE | Online – 19 February 2016 – Information regarding advanced cancer patients followed at home who are admitted to the hospital in the last days of life are lacking. Of 550 consecutive patients followed at home, 138 (25.1 %) were admitted to the hospital. Younger patients were more likely to die in the hospital. In a logistic risk analysis adjusted for age, patients with lung and head-neck cancer were more likely to die in the hospital. Patients having a female relative or a female consort as a caregiver were more likely to die at home. The most frequent reason for hospital admission was dyspnea. Admission was more frequent to the oncology ward. Patients who were admitted to the hospital died after a mean of 10.2 days. http://goo.gl/EmhwmA

Cont. next page

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

Selected articles on hospital admissions at end of life

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 24 December 2015 – **'Why do home hospice patients return to the hospital? A study of hospice provider perspectives.'** In the U.S., approximately 25% of patients who disenroll from hospice are hospitalized. Eight major themes were identified: 1) Not fully understanding hospice; 2) Lack of clarity about disease prognosis; 3) Desire to continue receiving care from non-hospice physicians and hospital; 4) Caregiver burden; 5) Distressing/difficult-to-manage signs and symptoms; 6) Caregivers' reluctance to administer morphine; 7) 911's faster response time compared to hospice; and, 8) Families' difficulty accepting patients' mortality. [Noted in Media Watch, 4 January 2016, #443 (p.13)] http://goo.gl/rajdC8

- *PALLIATIVE MEDICINE*, 2014;28(7):917-918. **'Avoidable for whom? Hospital use at the end of life.'** A policy concern in many countries is reducing the number, and length, of acute hospital admissions among people who are at the end of life. This is typically presented as a "win-win" situation as a "good death" is viewed as hard to achieve in a hospital setting. Papers in this edition of *Palliative Medicine* add to a growing body of evidence which indicates that, while this argument may appear both appealing and straightforward on paper, the realities of dying are more complex and unpredictable.[1,2] [Noted in Media Watch, 9 June 2014, #361 (p.11)] http://goo.gl/dcAGlO

    1. 'What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses,' *Palliative Medicine*, 2014;28(7):**941-948.** [Noted in Media Watch, 24 February 2014, #346 (p.13)] http://goo.gl/XaTySH

    2. 'General practitioners' perspectives on the avoidability of hospitalizations at the end of life: A mixed method study,' *Palliative Medicine*, 2014;28(7):**949-958.** [Noted in Media Watch, 7 April 2014, #352 (p.13)] http://goo.gl/hviNaJ

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 7 April 2014 – **'Rehospitalization of older adults discharged to home hospice care.'** Among those patients readmitted, 25% had received a palliative care consultation, compared to 47.1% of those not readmitted. Patients without a participating decision-maker involved in their hospice decision had 3.5 times the risk of readmission within 30 days, compared to those with. Readmission within 30 days of initial discharge to hospice is associated with several measures of care and care planning. [Noted in Media Watch, 14 April 2014, #353 (p.12)] http://goo.gl/ZfFb4U

Trends in scientific publishing: Dark clouds loom large

JOURNAL OF THE NEUROLOGICAL SCIENCES | Online – 17 February 2016 – The world wide web has brought about a paradigm shift in the way medical research is published and accessed. The ease with which a new journal can be started/hosted by publishing start-ups is unprecedented. The tremendous capabilities of the world wide web and the open access revolution when combined with a highly profitable business have attracted unscrupulous fraudulent operators to the publishing industry. The intent of these fraudulent publishers is solely driven by profit with utter disregard to scientific content, peer reviews and ethics. This phenomenon has been referred to as "predatory publishing." The "international" tag of such journals often betrays their true origins. http://goo.gl/5w9ept

N.B. Selected articles on predatory journals are listed in the issues of Media Watch of 23 November 2015, #437 (p.11) and 8 February 2016, #448 (p.9).

Extract from the *Journal of the Neurological Sciences* article

The gold open access model of publishing, where the author pays the publisher, when coupled with a non-existent peer review threatens to blur the distinction between science and pseudoscience. The average researcher needs to be made more aware of this clear and present danger to the scientific community. Prevention is better than cure.

Editorial

The pendulum swings for opioid prescribing

JOURNAL OF PALLIATIVE MEDICINE | Online – 23 February 2016 – For most of the 20th century, a common belief among the public, including physicians, is that an opioid like morphine, even if prescribed by a physician for a medical indication, causes addiction. The consequence was extraordinary and unnecessary suffering after surgical operations, trauma, and cancer. The worst thing I read was advice in the *Journal of the American Medical Association* in a paper written in the 1940s that, when a doctor prescribes morphine to a patient dying of cancer in the hospital, he should alternate "real" drug with *placebo* in order to see if the patient really needs the drug. Yikes! The 1990s and 2000s saw an increase in the willingness of physicians to prescribe opioids because of the correction of this fundamental misunderstanding. Although we learned that pain is complex, and multifactorial, and that opioids are good for some kinds of pain (e.g., cancer pain, postoperative and posttraumatic pain), there are other kinds of pain (e.g., muscle strain, low back pain without radiological abnormalities) where it doesn't work at all. But nuance doesn't make for good marketing, and opioids as all-around safe analgesics for everything that hurts made for promiscuous prescribing. The pendulum swung to the other end of its arc. Please be a voice to stop the pendulum from swinging. Where you can, reach out to stop the swing and bring it to rest where it is at rest. http://goo.gl/rDY6wn

Negative outcomes of unbalanced opioid policy supported by clinicians, politicians, and the media

JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY | Online – 18 February 2016 – Harmful and non-medical use of prescription opioids has increased precipitously in the U.S. and some other countries in recent years, but not everywhere around the world. Addressing this problem requires attention to scientific data and to objective and balanced consideration of factors driving the problems. Unfortunately, the situation has been blurred by some politicians, health professionals, and the media by their using inadequate concepts, misrepresenting and exaggerating facts, and demonizing pain patients. The authors analyze what has occurred and present what they believe to be a balanced view of the problems. http://goo.gl/nQ1orX

End-of-life care Minnesota, U.S.

Palliative care in rural Minnesota: Findings from Stratis Health's Minnesota Rural Palliative Care Initiative

MINNESOTA MEDICINE, 2016;99(1):39-41. Palliative care (PC), which involves managing symptoms, controlling pain and addressing stress caused by a chronic or terminal illness, has been shown to keep patients out of the hospital and allow them to stay home and live more comfortably with their illness. Typically, it is provided by an interdisciplinary team led by a physician trained in palliative medicine. Rural areas have not always had access to such specialists. Yet, today, rural health care organizations are finding ways to create PC programs that meet the needs of their chronically ill and aging populations. This article describes a six-year initiative led by Stratis Health to advance PC in rural Minnesota. It highlights the work of FirstLight Health System in Mora and describes Stratis Health's Rural Palliative Care Measurement Pilot Project, an effort to develop and test measures for evaluating rural PC programs.

Misunderstood speciality: Many physicians still don't understand how palliative care works and how it differs from hospice

MINNESOTA MEDICINE, 2016;99(1):10-17. Drew Rosielle MD, director of the University of Minnesota's hospice and palliative care (PC) fellowship program, believes that once more physicians are trained in palliative medicine the question will change from, "When should a patient see a palliative medicine specialist?" to "When can a patient's PC needs be met by a primary physician who's been trained in basic PC?"

N.B. Journal contents page (click on title of article of interest to access full text): http://goo.gl/b0Tivz.

Cont.

Related

- *American Journal of Hospice & Palliative Medicine* | Online – 27 February 2016 – **'U.S. physicians overwhelmingly endorse hospice as the better option for most patients at the end of life.'** Ninety-eight percent of physicians agreed that hospice provides better care at the end of life than the patient would receive without hospice. Only 11% of physicians agreed that patients who enter hospice miss out on medical interventions from which they would have benefitted. Ninety-two percent encouraged at least 1 patient to consider hospice in the previous 12 months. Oncologists were the most ambivalent about whether patients who enter hospice miss out on beneficial interventions, but they also referred more patients to hospice than physicians from other specialties. http://goo.gl/6SbONt

Moving the integration of palliative care from idea to practice

PALLIATIVE MEDICINE, 2016;30(3):197-199. Even though several aspects of integration are already described and are being investigated in current research initiatives, including interesting practice examples, barriers are still apparent with regard to education, implementation and policy. Therefore, more empirical work is needed, both with a clinical and a policy perspective, to unravel constitutive elements of better integration of palliative care (PC) in current health systems and practices for the benefit of patients and their relatives. The importance of further PC integration is not at all expected to be diminishing as cancer and chronic diseases will increase, and these patients often develop PC needs. Next steps are therefore to a) identify, describe and evidence best practices of integrated PC; b) identify barriers and opportunities for greater integration of PC in national health systems including clinical, service provider, education, implementation, informal caregiving and regulatory levels; and, c) develop and implement comprehensive implementation strategies to overcome barriers and to take PC integration forward. In this respect, current attempts to develop national PC programmes (e.g., Ireland, The Netherlands) need careful consideration, and the implementation of adequate indicators to monitor the proceedings of PC integration internationally should be taken forward. http://goo.gl/swyhZ5

How healthcare systems evaluate their advance care planning initiatives: Results from a systematic review

PALLIATIVE MEDICINE | Online – 23 February 2016 – Advance care planning (ACP) initiatives are being implemented across healthcare systems around the world, but how best to evaluate their implementation is unknown. Peer-reviewed and gray literature searches were conducted till February 2015 to answer: "What methods have healthcare systems used to evaluate implementation of ACP initiatives?" A total of 46 studies met inclusion criteria for analysis. Most articles reported on single parts of a healthcare system (e.g., continuing care). The most common outcome measures pertained to document completion, followed by healthcare resource use. Patient-, family-, or healthcare provider-reported outcomes were less commonly measured. Concordance measures (e.g., dying in place of choice) were reported by only 26% of studies. The conceptual quality indicator framework identified gaps and redundancies in measurement and is presented as a potential foundation from which to develop a comprehensive ACP evaluation framework. Document completion is frequently used to evaluate ACP program implementation; capturing the quality of care appears to be more difficult. http://goo.gl/LrIQdC

Parental physical proximity in end-of-life care in the PICU

PEDIATRIC CRITICAL CARE MEDICINE | Online – 17 February 2016 – Health professionals in PICUs support both child and parents when a child's death is imminent. Parents long to stay connected to their dying child but the high-tech environment and treatment implications make it difficult to stay physically close. Parents [i.e., study participants] vividly remembered the damage done to the child's physical appearance, an inevitable consequence of medical treatment. They felt frustrated and hurt when they could not hold their child. Yet they felt comforted if facilitated to be physically close to the dying child, like lying with the child in one bed, holding the child in the hour of death, and washing the child after death. Parents' experiences suggest that aspects of physicality in medical settings deserve more attention. Better understanding of the significance of bodily aspects-other than pain and symptom management-improves end-of-life support and should be part of the humane approach to families. http://goo.gl/6NClXj

The role of speech-language pathologists in palliative care: Where are we now? A review of the literature

PROGRESS IN PALLIATIVE CARE | Online – 19 February 2016 – Dysphagia and communication changes are common in life-limiting conditions and Speech-Language Pathology (SLP) involvement to facilitate effective communication, eating and drinking contributes to the goals of comprehensive palliative care. Specific roles for SLPs in dysphagia, communication, and holistic professional practice were identified. There is insufficient research to determine whether this is reflected in everyday SLP practice. Potential challenges to providing services include the impact of working with people who are dying, limited professional preparation, ongoing education constraints, and legal and ethical considerations. Further research into SLP activities with patients with life-limiting conditions is required to explore the valuable contributions already being made by SLPs to the care of patients with life-limiting illnesses and to identify opportunities to develop and improve evidence-based services in this area. http://goo.gl/XlC1ny

Noted in Media Watch, 16 March 2015, #401 (p.11):

- *PALLIATIVE MEDICINE* | Online – 11 March 2015 – **'Perspectives on the role of the speech and language therapist in palliative care: An international survey.'** Internationally, speech and language therapists believe they have a role in palliative care. Respondents highlighted that this area of practice is under-resourced, under-acknowledged, and poorly developed. http://goo.gl/FacRt9

Noted in Media Watch, 14 May 2012, #253 (p.6):

- *TOPICS IN LANGUAGE DISORDERS*, 2012;32(2):137-148. **'Integrating speech-language pathology services in palliative end-of-life care.'** This article describes how the role of the speech-language pathologists (SLP) in palliative care services contrasts with more traditional impairment-based rehabilitation roles. Case examples illustrate how SLPs interact within an end-of-life care team, highlighting the importance of effective inter-professional communication. http://goo.gl/sI0aaR

Why do adults with palliative care needs present to the emergency department? A narrative review of the literature

PROGRESS IN PALLIATIVE CARE | Online – 19 February 2016 – Given the increasing emphasis on community-based provision of palliative care (PC) and the view that good dying should occur at home, it is unsurprising that policy in many countries has started focusing on preventing hospital admissions at the end of life. However, little attention has been paid to the role of the emergency department (ED) in this regard, despite the fact that a high proportion of hospital admissions among patients with PC needs originate in the ED. The "reason" for a patient's presentation was largely defined as their "presenting complaint" or "underlying diagnosis." There was consistency in the studies in this respect; the majority found that people with lung cancer and those experiencing distressing respiratory symptoms were most likely the present to the ED. Subsequently, pain and gastrointestinal symptoms such as nausea and vomiting were uniformly found to be most common. The three prospective studies gathered information about reason for presentation from the patient perspective using structured questionnaires, but no study collected qualitative data from patients and families. The data does not facilitate a detailed discussion about the difficulties that this population of patients face, and whether they may be best managed in an acute or community setting. http://goo.gl/H2ko6X

Selected articles on palliative care in the emergency department

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(1):19-23. **'When home care falters: Out-of-hours visits to the emergency department.'** Strategies to decrease out-of-hours admissions to the ED include implementing timely advance care planning, proactively managing common symptoms, educating patients and carers, and providing respite for carers where possible. [Noted in Media Watch, 8 February 2016, #448 (p.10)]

  N.B. Access to this article requires a subscription. Journal contents page: http://goo.gl/qlWex7

Cont.

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 August 2015 – **'Palliative care screening and assessment in the emergency department: A systematic review.'** The authors identify multiple studies demonstrating that screening and referral for palliative care consultation is feasible. They recommend a screening framework based on a synthesis of available evidence. [Noted in Media Watch, 7 September 2015, #426 (p.13)] http://goo.gl/LbYL6Q

- *PALLIATIVE MEDICINE* | Online – 29 January 2015 – **'What's in a name? A qualitative exploration of what is understood by "palliative care" in the emergency department.'** There are entrenched contradictions and tensions surrounding the term "palliative care" and confronting these is likely to require more than "re-branding," and will promote better care for this vulnerable patient group... [Noted in Media Watch, 9 February 2015, #396 (p.11)] http://goo.gl/nLdAKQ

Unresolved grief and its consequences. A nationwide follow-up of teenage loss of a parent to cancer 6-9 years earlier

SUPPORTIVE CARE IN CANCER | Online – 22 February 2016 – In a nationwide population-based study [in Sweden] of 622 of 851 (73 %) youths who as teenagers 6 to 9 years earlier had lost a parent to cancer, the authors explored the magnitude of unresolved grief and its association with psychological and physiological morbidity. Approximately half of cancer-bereaved youth report no or little grief resolution 6 to 9 years post-loss, which is associated with fatigue, sleeping problems and depressive symptoms. http://goo.gl/b9m3H7

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *DEUTSCHE MEDIZINISCHE WOCHENSCHRIFT*, 2016;141(4):32-37. **'Assisted suicide in Germany: Medical diagnoses and personal reasons of 117 decedents.'** In Germany both scientific and public debates on physician assisted suicide often focus on patients with unbearable suffering in terminal condition. Proponents of physician assisted suicide bring forward the argument that there are end-of-life situations where only assisted suicide can bring relief from intolerable pain, dyspnea or other symptoms. But does focusing on unbearable symptoms in terminal condition reflect the reality of assisted suicide? The authors' data from 117 assisted suicides in Germany indicates that the reasons for assisted suicide are more complex than the current debate in Germany suggests. Between 2010 and 2013 Sterbehilfe Deutschland (StHD) provided assistance in 118 suicides. Loss of life perspective in the face of a severe disease, fear of long-term care and weariness of life without any severe disease rather than unbearable suffering of non-treatable symptoms seem to be the most common reasons for members of StHD to commit suicide. These empirical findings should be mentioned in future debates on assisted suicide in Germany. http://goo.gl/7ASRuV

  N.B. German language article.

- *JOURNAL OF ASSISTED DYING*, 2016;1(1):1-6. **'Physician use of misinformation to speculate "assisted dying suicide contagion" in Oregon.'** Several physicians have speculated about Oregon suicide statistics in a manner that is not supported by the cited publications, or by public Centers for Disease Control & Prevention mortality database data. The claims variously: a) Misrepresent key data in the publications; b) omit information in the publications that is at variance with suicide contagion speculation; and, c) overlook other significant information at variance with speculation. The physicians have previously acknowledged inability to prove perceived "slippery slope" effects of the Dying With Dignity Act. Other opponents of the Act have republished the physicians' erroneous information. http://goo.gl/XmEAGv

Worth Repeating

Supporting family caregivers at the end of life: "They don't know what they don't know"

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2004;291(4):483-491. Even for patients receiving complex, intensive medical care for serious and life-threatening illness, family caregiving is typically at the core of what sustains patients at the end of life (EOL). The amorphous relationship between physicians and the families of patients at the EOL presents both challenges and opportunities for which physicians may be unprepared. Families play important roles in the practical and emotional aspects of patient care and in decision making at the EOL. At the same time, family members may carry significant burdens as a result of their work. Through the perspectives of the wife, daughter, and home care nurse of a patient who died from pancreatic cancer, the authors illustrate the range of family caregiver experiences and suggest potentially helpful physician interventions. They describe five burdens of family caregiving (time and logistics, physical tasks, financial costs, emotional burdens and mental health risks, and physical health risks), and review the responsibilities of physicians to family caregivers. Based on available evidence, the authors identify five areas of opportunity for physicians to be of service to family members caring for patients at the EOL, including promoting excellent communication with family, encouraging appropriate advance care planning and decision making, supporting home care, demonstrating empathy for family emotions and relationships, and attending to family grief and bereavement. In caring well for family caregivers at the end of life, physicians may not only improve the experiences of patients and family but also find greater sustenance and meaning in their own work. http://goo.gl/wvrXWb

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.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
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/zIuyY9

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

---

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net