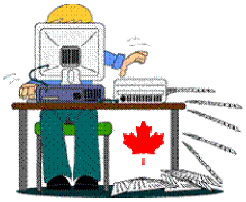
Media Watch...
*is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care,** and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.*

25 April 2016 Edition | Issue #459



Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down Specialist Publications and 'The unprepared caregiver' (p.10), in *The Gerontologist*.

Canada

The next court challenge: The right to better care

THE GLOBE & MAIL | Online – 19 April 2016 – Supreme Court of Canada decisions do not end litigation or stop debate. More typically, they spawn new challenges. Carter *et al*, the 2015 decision on physician-assisted termination, is no exception. Last week, the government introduced legislation promising a new standard permitting qualified medical personnel to end a patient's life in certain well-defined circumstances. The proposed legislation – reviled by both the left and right – is a cautious first step reflecting the Supreme Court's judgment. The next court challenge will focus on the often unmet needs of Canadians with chronic conditions who need but are not receiving adequate palliative care (PC), rehabilitative support and social services. Those are the things needed to live with dignity despite restrictions, and in too many communities in Canada they are unavailable. If there is to be choice under the court's guidelines, it must be full rather than restricted. Expert PC can mitigate physical suffering in, according to experts, perhaps 95% of all cases. But at present that level of pain control is unavailable to many Canadians. Without its surety, the choice is limited, if not empty, and justice therefore denied because a real, full choice is withheld. Similarly, all agree that end-stage home care and hospice care can make the last stage of an illness more than bearable. But many Canadians who would choose this cannot. It's not available. And without its assurance, the choices they are offered for care to the end are limited. http://goo.gl/mdkF0b

Reprise: Access to palliative care in Canada

In 2005, Senator Sharon Carstairs, Canada's first and only Minister with Special Responsibility for Palliative Care (2001-2003), had estimated no more than 15% of Canadians had access to palliative care (PC). In 2007, in the only statistically significant study published to that date, the Canadian Institute for Health Information estimated people living with a terminal illness in British Columbia, Alberta, Saskatchewan and Manitoba were referred to PC only 35-37% of the time; a low of 16% if the terminal illness was *not* cancer. A 2009 Université Laval press release estimated the number at 10%. In recent years, the Canadian Hospice Palliative Care Association estimates have varied from a low of 15% to a high of 30%. The Quality of End-of-Life Care Coalition of Canada has been even less specific – "only a small portion of those who die receive PC."

Access to pediatric PC? A 2007 study indicated that "only a small percentage (5-12%) of children who die in Canada receive specialized end-of-life care (EOLC)." ***BRA***

N.B. For a listing of nine key studies on EOLC in Canada, published between 1995-2014, see the 22 December 2014 issue of Media Watch, #389 (p.4).

End-of-life care: Assist your loved ones with clear instructions

THE GLOBE & MAIL | Online – 19 April 2016 – With the introduction of Bill C-14 (medical assistance in dying legislation), the debate around assisted death is hitting a fever pitch. But let's not forget that, no matter what the final legislation looks like, very few people will actually avail themselves of a hastened death. About 99% of people will die the way they do now – in a highly predictable but largely unplanned manner. As a result of this lack of planning – and, in large part, our squeamishness in talking about death when we're well – far too many patients will die in a manner that's completely at odds with their personal wishes. If you want your wishes respected, you have to express them. Most Canadians don't do so. http://goo.gl/qGJWTd

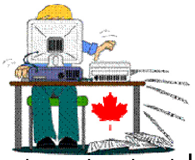
Term "palliative care" misperceived as always meaning certain death: Researchers

ONTARIO | *Metro News* (Toronto) – 18 April 2016 – A new study suggests a perception of palliative care (PC) as being synonymous with death is preventing many patients from accessing supportive therapies aimed at improving their quality of life.[1] Lead researcher Dr. Camilla Zimmermann of the Princess Margaret Cancer Centre in Toronto says PC can offer pain and other symptom control from diagnosis and through the course of a patient's illness. And she says not all patients referred for PC end up dying from the disease for which they are being treated. Some may live for several years following diagnosis. The study ... compares perceptions of the term "palliative care" among cancer patients who received the extra care versus those who got only standard treatment. Zimmermann says those enrolled in PC changed their view dramatically and saw the service as beneficial to their quality of life, while patients who didn't continued to see it as frightening. But she says even patients in the intervention group still felt stigmatized by the label "palliative care" and believed it should be renamed or rebranded. http://goo.gl/Hz8C9M

1. 'Perceptions of palliative care among patients with advanced cancer and their caregivers,' *Canadian Medical Association Journal*, 18 April 2016. http://goo.gl/3V0xPd

Selected articles on defining end-of-life care

- *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
- *THE ONCOLOGY REPORT* | Online – 10 April 2013 – **'Is the moniker "palliative care" too loaded?'** A survey of 169 patients with advanced cancer found those randomized to hear the term "supportive care" instead of "palliative care" rated their understanding, overall impressions and future perceived need for those services significantly higher. [Noted in Media Watch, 15 April 2013, #301 (pp.14-15)] http://goo.gl/lD9oqX
- *SUPPORTIVE CARE IN CANCER* | Online – 31 August 2012 – **'Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks.'** In this literature search commonly used terms were rarely and inconsistently defined in the palliative oncology literature. [Noted in Media Watch, 3 September 2012, #269 (p.7)] http://goo.gl/XHxTD5



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:

- *THE TORONTO STAR* | Online – 22 April 2016 – '**Assisted suicide could violate charter of rights, Liberals acknowledge.**' In a written explanation of the reasoning behind the proposed new law on medical assistance in dying, the Justice Department acknowledges that the bill could violate the charter of rights on a number of fronts. They include: excluding those who are suffering intolerably, but whose natural death is not reasonably foreseeable could violate the right to life, liberty and security of the person; treating people differently on the basis of their different medical conditions could violate equality rights; not allowing advance directives could force those with competence-eroding conditions like dementia to take their lives prematurely or risk permanently losing access to medically assisted death once they no longer have capacity to consent, thereby violating equality rights and the right to life, liberty and security of the person; restricting access to adults at least 18 years of age could violate the right not to be discriminated against based on age; and, requiring two independent people to witness a written request for medical assistance in dying could violate privacy rights. However, the analysis argues that the bill strikes an appropriate balance that respects "autonomy during the passage to death" while otherwise prioritizing respect for life. It also "furthers the objective of suicide prevention and the protection of the vulnerable." http://goo.gl/W3EmO4

Specialist Publications

'How is death hastening done? A Review of existing sanctioned death hastening decision making processes and practice' (p.13), in *International Journal of Nursing Student Scholarship.*

'Converting the "right to life" to the "right to physician-assisted suicide and euthanasia": An analysis of *Carter v. Canada (Attorney General), Supreme Court of Canada*' (p.13), in *Medical Law Review.*

U.S.A.

Rural Access to Hospice Act 2016

Legislation to expand rural hospice care

POLITICAL NEWS | Online – 18 April 2016 – Bipartisan legislation to improve access to hospice care in rural America has been tabled in the Senate. Only 32% of those eligible in rural areas utilize hospice compared to 48% in urban areas, according to a report from the Medicare Payment Advisory Commission. The Rural Access to Hospice Act of 2016 aims to level the playing field. When patients enroll in hospice they select a physician or nurse practitioner to serve as their attending physician. Unlike other services, rural health clinics and federally qualified health centers cannot bill Medicare under Part B for hospice, which prevents some patients from receiving care from their trusted primary physician. The Act would provide a technical fix to this existing statutory barrier and allow rural health clinics and federally qualified health centers to receive payment for physicians' services in hospice care. http://goo.gl/paarBo

Noted in Media Watch, 18 April 2016, #458 (p.4):

- WYOMING | *The New York Times* – 8 April 2016 – '**Alone on the range, seniors often lack access to health care.**' When he began to weaken from heart failure in December, all Bill Kolacny wanted was to die in their log home on the Clark Fork River. But, the nearest hospice organization, in Red Lodge, Montana, isn't licensed to care for patients in Wyoming. And the closest Wyoming hospice said it couldn't afford to send staff members 60 miles to the Kolacny ranch. http://goo.gl/yHaFw8

N.B. Listed in this issue of Media Watch are back issues of the weekly report in which articles on end-of-life care in rural communities and remote regions are listed or noted.

When a doctor and patient disagree about care at the end of life

THE WASHINGTON POST | Online – 18 April 2016 – Medicare recently put in place new rules that will allow doctors to be reimbursed for discussing end-of-life (EOL) preferences with patients. Originally derailed by the "death panel" accusations of 2010, the measure has been hailed as a major victory toward a better, more transparent system of EOL care. Patrick Conway, the chief medical officer for the Centers for Medicare & Medicaid Services, remarked that such advance care planning discussions were important to promote "patient- and family-centered care." But sometimes these discussions are anything but patient-centered. That's because what the doctor wants doesn't always align with what the patient needs. While 8 in 10 people of all ages think it is important to talk to their doctor about their EOL wishes, fewer than 1 in 10 report actually having had these discussions. But there are two participants in those EOL conversations: patient and doctor. Unless each realizes what the other wants, both risk coming away from those conversations feeling uncomfortable or sensing that things had not gone well. https://goo.gl/YWGOQ3

Specialist Publications

'Restricting symptoms before and after admission to hospice' (p.11), in *American Journal of Medicine.*

'Who knew? Hospice is a business. What that means for all of us' (p.11), in *The Gerontologist.*

'Prevalence and predictors of burnout among hospice and palliative care clinicians in the U.S.' (p.11), in *Journal of Pain & Symptom Management.*

'Why the interdisciplinary team approach works: Insights from complexity science' (p.11), in *Journal of Palliative Medicine.*

'Interdisciplinary team care and hospice team provider visit patterns during the last week of life' (p.11) in *Journal of Palliative Medicine.*

Related

- WASHINGTON DC | *Modern Healthcare* – 19 April 2016 – **'Teaching young physicians how to say no to aggressive end-of-life care.'** Nneka Sederstrom, director of the Center of Ethics at MedStar Washington Hospital Center in Washington DC about seven years ago noticed that medical residents at the hospital seemed overly stressed. She set out to discover why. Sederstrom began a program that replaced the standard ethics lecture given all residents with something she called 'Moral Distress Rounds.' During the sessions, she asked young residents about the primary cause of stress in their jobs. "We discussed the issues that were causing them to stress, and they were all related to end-of-life care," Sederstrom said. http://goo.gl/Kcw2Sq

- *THE NEW YORK TIMES* | Online – 14 April 2016 – **'In the hospital, resisting the urge to do more.'** Our training [in the ICU] urges us on, even when it is clear our patient is dying, and especially if there is no family to consent to putting the brakes on. And so my intensive care instincts urged me on. There were many things I could imagine doing. Lowering the acid level in the blood with bicarbonate, draining the fluid from her belly, increasing the blood pressure medications, starting dialysis. I watched as my residents ran in and out of the room, procuring the various catheter kits that would be threaded into her body to perform these functions. But I felt another pull too, from another part of my medical training – palliative care. http://goo.gl/kQftGC

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

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MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE

Please feel free to share this weekly report with your colleagues.
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MW 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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Hospice program gives prisoners a chance to die, and live, with dignity

OHIO | *The Blade* (Toledo) – 17 April 2016 – Roughly 120 people a year die in Ohio prisons. Dozens or even hundreds more are medically incapacitated, including paraplegics, quadriplegics, and those suffering from Alzheimer's disease and dementia. They pose no risk to society, but cost the state millions of dollars a year in medical expenses that Medicare, Medicaid, or private insurance would cover if they were released. Still, nearly all of them will remain in prison. Ohio has no timely and expedient way to release dying and medically incapacitated inmates. For [Gary] Ferrell, time is running out. Five months ago, while serving a seven-year sentence at Marion Correctional Institution for trying to rob a store in Columbus, Ferrell learned he had about six months to live. An alcoholic, he was diagnosed with terminal liver cancer. Ferrell was transferred to Franklin Medical Center. Prisoners Ferrell and [Scott] Abram, a volunteer lay counselor, are part of a new prison hospice program that uses about a dozen inmate volunteers ... to help other prisoners die with dignity. Prisoner lay counselors are joined by community volunteers... in singing to prisoners, reading their letters, playing cards with them, helping them make out commissary requests, and making the lives of dying inmates better. In doing so, they make their own lives better. Nationwide, there are an estimated 70 prison hospice programs, but only a few, including programs in Louisiana, Ohio, and California, use other inmates as volunteers trained in end-of-life care. By helping dying prisoners, inmate volunteers have an opportunity to give back. http://goo.gl/hl0Df7

Updated Prison Hospice Backgrounder

End-of-life care – or the lack of – in the prison system has been highlighted on a regular basis in Media Watch. An updated compilation of the articles, reports, etc., noted in past issues of the weekly report can be downloaded at the Palliative Care Community Network website: http://goo.gl/qgd4hp

- OHIO | *The Blade* (Toledo) – 17 April 2016 – **'Editorial: Going home to die.'** Prison is a hard place to live, and an even harder place to die. Ohio should provide expedient ways to release dying and other incapacitated prisoners. That would be humane and cost-effective by shifting millions of dollars of state medical expenses to federally funded Medicare and Medicaid coverage. More than 120 people a year die in Ohio state prisons. That number will grow as the prison population continues to gray. Ohio state prisons hold 9,000 inmates older than 50, nearly double the number in 2001. Older prisoners now account for almost 20% of the population. http://goo.gl/6kAgNS

International

Four out of 10 Malaysians need palliative care each year

MALAYSIA | *The Malay Mail* (Jalan) – 22 April 2016 – Four out of 10 Malaysians will require palliative care (PC) at the end of their lives. This translates to an estimated 56,000 patients each year and this number is growing as the population ages. More than 60% of the needs arise from patients suffering from non-cancer illnesses. And even more worrisome, less than 10% of them have access to this essential aspect of medical care. When PC first started, it was out of a sense that patients with life-threatening illnesses were being abandoned when cure was no longer possible. These patients were suffering and PC was a humane response to their suffering. As a leading PC service provider in the country, and a strong advocate for better access and improved standards in this medical specialty, Hospis Malaysia has produced a report...[1] http://goo.gl/6lfsrJ

1. 'Palliative Care Needs Assessment: Malaysia,' April 2016. Hospis Malay. https://goo.gl/NSQqFQ

N.B. Malaysia was ranked 38th 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

End-of-life care in New Zealand

Hard subjects tackled in new guide

NEW ZEALAND | *The Northern Advocate* (Whangarei) – 20 April 2016 – Dying and death are difficult subjects at the best of times and even more so when public resources that are available are not culturally appropriate. So to help make the subjects easier to deal with, Northland District Health Board (DHB) has created a new resource to help make it easier for Māori – a carved waka [watercraft] to ease the journey. “We know through literature and research that the discussions around advance care planning (ACP) are different for Māori and non-Māori, Pacific peoples, migrants, everyone,” Northland DHB director of nursing and midwifery Margareth Broodkoorn said. In 2014, a Northland Māori ACP working group was established and in 2015, the group hosted two co-design hui (assembly) to consult with consumers and health-care workers. As a result “He Waka Kakarauri”[watercraft twilight] – a model to engage Māori in conversations that are important for future health and end of life care needs – was developed. “Based on a waka model, people are encouraged to have conversations about their health, when they are well and when they are sick, dying or have died – that are tika [right], pono [true] and aroha [shared with love], and are held at a time and in an environment that is culturally appropriate to Māori,” she said. http://goo.gl/jO9IGR

> **N.B.** Additional articles on Māori beliefs and practices in the context of end-of-life care are noted in the issues of Media Watch of 7 March 2016, #452 (p.10), 15 June 2015, #414 (p.5), 16 June 2014, #362 (p.8), and 17 March 2014, #349 (p.9).

Call for “major improvements” in United Arab Emirates’ care of the dying

UNITED ARAB EMIRATES | *The National* (Abu Dhabi) – 19 April 2016 – Care of the terminally ill is being hampered by out-of-date laws on resuscitation and misplaced fears over opiate addiction. A taskforce on the issue has also found symptoms are often improperly diagnosed and there is a shortage of options for advanced pain management. The drawbacks mean the United Arab Emirates has no chance of meeting World Health Organisation global targets for palliative care (PC) by 2020.[1] “The challenges are huge,” said Nesreen Al Alfi ... a member of the Health Authority Abu Dhabi taskforce looking at where improvements can be made. “Even when the language and culture barriers are down, I still see defects in caring for those patients because of a lack of training and structured programmes for PC.” http://goo.gl/vSWIgm

1. ‘Global Atlas of Palliative Care at the End of Life,’ World Health Organisation and the Worldwide Palliative Care Alliance, January 2014. [Noted in Media Watch, 3 February 2014, #343 (p.5)] http://goo.gl/xocybm

Noted in Media Watch, 19 January 2015, #393 (p.5):

- UNITED ARAB EMIRATES | Zawya (Dubai) – 13 January 2015 – **‘Healthcare experts in the region call for further development of palliative care for severely ill patients in the Middle East.’** Palliative care (PC) remains underdeveloped in the Middle East. A few Arab countries such as Lebanon, Kuwait, Saudi Arabia, Sudan, Egypt, and Jordan have limited PC services, but most Middle Eastern countries do not have any PC at all. https://goo.gl/WuBZTf

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

End-of-life care in England

Doctors still failing to tell families that loved ones could die imminently

U.K. (England) | *The Daily Express* – 19 April 2016 – An end-of-life care (EOLC) audit by the Royal College of Physicians, shows people deemed important to the dying patient were notified of their imminent deaths in only 84% of cases – excluding those which were sudden or unexpected.[1] The audit ... found there was 'room for improvement' in round the clock palliative care. The audit collected data from May 1 to 31, 2015, from the records of 9,302 patients records across 142 National Health Service organisations in England – mostly acute hospitals trusts. In only 25% of people recognised as likely to die was there documented evidence of a discussion with a health care professional about their "likely imminent death." For 63.4% of those patients the discussion wasn't possible because of unconsciousness, dementia, and reduced capacity to understand the conversation, however leaving 12% of cases undocumented. Seven per cent of patients whose death was deemed "predictable" did not have documentation saying they would probably die. In 76% of cases, where a person was receiving EOLC, a senior doctor was involved in making sure a person knew they were dying. The results were compared to an audit carried out in 2013 and published in 2014.[2] http://goo.gl/mZUYjb

Specialist Publications

'End-of-life care still not living up to public and doctors' expectations' (p.9), in *British Medical Journal.*

1. 'End-of-Life Care Audit – Dying in Hospital: National Report for England 2016,' Royal College of Physicians, March 2016. https://goo.gl/7RZixA

2. 'End-of-Life Care Audit – Dying in Hospital: National Report for England 2013,' Royal College of Physicians, 14 May 2014. http://goo.gl/TJlJqy

Related

- U.K. | *The Independent* (Dublin, Ireland) – 22 April 2016 –'**Dying people not getting enough help to eat or drink and are dying in pain: Survey.**' One in five people who saw their relative or friend die last year also felt decisions were taken about their care that the person would not have wanted. Furthermore, hospital doctors and nurses showed less dignity and respect for loved ones than those working in other places, such as care homes and hospices. More than 20,000 relatives and friends of people who died last year shared their views of end-of-life care for an Office for National Statistics survey. http://goo.gl/sj4oSh

- U.K. (England) | ITV News – 21 April 2016 – **'Hospice funding crisis...'** An exclusive investigation by Granada [TV] has revealed that some hospices in the North West may have to shut because of a funding crisis. Bosses have told our politics show that fewer people are donating money to support end-of-life care. And government funding has been cut or frozen. http://goo.gl/lQSq4w

- U.K. | *The Daily Mirror* – 17 April 2016 – **'Where would YOU like to die? Survey shows how we change our opinion as we get older,'** The question of where we would ideally like to die is something we all ponder from time to time. Most of us would probably say at home and many doctors would agree this is best, but not all. So is this always the best place to die? The value and emotional importance of home as a safe and private space may become spoiled. This could happen if your house turns into a ward annexe with the invasion of equipment and staff required. Patients and family members may find it distressing too. Regardless of preference, however, hospital will probably remain the place where most of us die for the foreseeable future. http://goo.gl/B6i0FD

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.

How history and paranoia keep morphine away from India's terminally-ill patients

INDIA | *India Quartz* – 18 April 2016 – A popular painkiller naturally derived from opium, morphine is a product of the poppy plant. India has been the leading producer of opium for decades, accounting for 90% of the global production... In 2011, the country exported 11.6 tonnes of it. Yet, within its own borders, India's Narcotic Drugs & Psychotropics Act 1985 has built a difficult obstacle course for health workers and patients trying to access morphine, at times requiring hospitals to have five separate licences. Even though farmers in states such as Uttar Pradesh and Rajasthan continue to grow poppy, only about 4% of Indians who need morphine actually received it in 2008, according to a Human Rights Watch report. Two years ago, the government moved to ease up on some restrictions, giving states more power over their programs. But progress has been slow, partly, experts say, because it's up against a legacy dating back to the Opium Wars. http://goo.gl/AUyaQ3

Specialist Publications

'The patient who "must not be told": Demographic factors associated with collusion in a retrospective study in South India' (p.12), in *Postgraduate Medical Journal*.

Noted in Media Watch, 21 December 2015, #441 (p.12):

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY*, 2015;29(4):412-415. **'Pain, palliative care, and compassion in India.'** An estimated one million new cases of cancer occur each year in India, with over 80% presenting at the point at which the disease is incurable. This narrative includes five case studies exploring differing aspects of palliative care: 1) Pain management; 2) Difficulties faced in accessing morphine; 3) Importance of compassion in end-of-life care; and, 4) Psychological effects on families. http://goo.gl/9yT4hl
- *HEALTH & HUMAN RIGHTS JOURNAL*, 2015;17(2):149-165. **'Evaluating a human rights-based advocacy approach to expanding access to pain medicines and palliative care: Global advocacy and case studies from India, Kenya, and Ukraine.'** The involvement of mainstream human rights organizations in advocacy around access to palliative care (PC) has lent credibility and specificity to the concept and helped generate a broad acceptance that PC is indeed a right. The authors efforts to advance an understanding and acceptance of access to PC as an element of the right to health were aided by recognition of the relationship between this right and two fundamental principles long recognized within human rights movements. http://goo.gl/0NeI42

N.B. India was ranked 67th 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

Losing a partner – the financial and practical consequences

U.K. | *The Actuarial Post* – 18 April 2016 – A new report ... reports the views of 500 people who had experienced bereavement in the last five years. The research finds seven in ten (69%) people who lost a partner were financially or practically unprepared for the loss. While death is a certainty we all face, only one in ten (11%) said they felt both financially and practically prepared when they lost their partner. Two in five (41%) had made a will and three in ten (30%) said they had talked about their funeral with their partner. A quarter (25%) had discussed the prospect of their partner dying, but very few had taken any practical steps or actions. http://goo.gl/LQU7xK

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

How much does care in palliative care wards cost in Poland?

ARCHIVES OF MEDICAL SCIENCE, 2016;12(2):457-468. The main task of palliative care (PC) units is to provide a dignified life for people with advanced progressive chronic disease through appropriate symptom management, communication between medical specialists and the patient and his family, as well as the coordination of care. Many PC units struggle with low incomes from the National Health Fund (NHF), which causes serious economic problems. The study showed a significant difference between the actual cost of PC units and the level of refund from the NHF. Based on the analysis of costs, the application has been submitted to the NHF to change the reimbursement amount of PC services... http://goo.gl/9gb7eb

> **N.B.** Poland was ranked 26th 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

End-of-life care in New Zealand

"That's not what you expect to do as a doctor, you know, you don't expect your patients to die." Death as a learning experience for undergraduate medical students

BMC MEDICAL EDUCATION | Online – 14 April 2016 – The authors could not find any medical education literature that discusses medical students learning about the social working environment of clinical institutions regarding how death is viewed and worked with on a daily basis. Given the reactions by students to their social working environment, this is an important area to consider so that novice clinical students can have another way of interpreting, and making sense of, their new and sometimes strange clinical environment. The death of a patient led to some transformative learning experiences for students [i.e., study participants], from changing their approach to the practice of medicine to shaping different personal views of death. An integrated curriculum of pre-clinical and clinical learning, with an emphasis on senior staff development on the hidden curriculum is needed. Thenceforth, staff can seize the opportunity to engage with students constructively, from a variety of contexts when they experience the death of a patient. https://goo.gl/UkRbsR

Editorial on end-of-life care in the U.K.

End-of-life care still not living up to public and doctors' expectations

BRITISH MEDICAL JOURNAL | Online – 18 April 2016 – As a society and as a medical profession we are apparently failing most people who die. Another report again calls for U.K. governments to prioritise and improve end-of-life care, particularly for those with non-cancer related illnesses.[1] This latest detailed British Medical Association report rates specialist palliative care (PC) for people with cancer as "excellent," while stating that PC for other conditions can be "poor" and "could frequently do much better." High quality care is not being delivered consistently. There are many examples of good progress, but poor communication, poor coordination, under-resourced services in the community, and limited public involvement persist and are cited as reasons for these ongoing failures. Furthermore, the report highlights that overtreatment is increasingly not only harming dying people but also precluding the addition of a PC approach with good, realistic, and proportionate care. http://goo.gl/xrXSjd

Quality of care delivered in the last 3 months of life for adults who died in England

'National Survey of Bereaved People (VOICES): 2015,' Statistical Bulletin, Office for National Statistics, April 2016. https://goo.gl/xJNHnB

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1. 'End-of-life care and physician-assisted dying,' British Medical Association, January 2016. (Scroll down to 'Reflections & Recommendations,' Volume 3) [Noted in Media Watch, 18 January 2016, #445 (p.4)] http://goo.gl/N4Cldm

Developing navigation competencies to care for older rural adults with advanced illness

CANADIAN JOURNAL ON AGING | Online – 19 April 2016 – This article describes the process used to engage experts – in rural aging, rural palliative care, and navigation – as well as rural community stakeholders to develop a conceptual definition of navigation and delineate navigation competencies for the care of this population. A discussion paper on the important considerations for navigation in this population was developed followed by a four-phased Delphi process with 30 expert panel members. Study results culminated in five general navigation competencies for health care providers caring for older rural persons and their families at end-of-life: 1) Provide patient/family screening; 2) Advocate for the patient/family; 3) Facilitate community connections; 4) Coordinate access to services and resources; and, 5) Promote active engagement. Specific competencies were also developed. http://goo.gl/y9axte

RURAL ONTARIO INSTITUTE

‘End-of-life care in rural communities.’ http://goo.gl/WPJvBI

‘National palliative medicine survey looks at urban versus rural.’ http://goo.gl/GEJL4u

N.B. Listed in Media Watch of 18 April 2016, #458 (p.4) are the back issues of the weekly report in which articles on end-of-life care in rural communities and remote regions are noted.

The unprepared caregiver

THE GERONTOLOGIST | Online – 21 April 2016 – Years of studying health care financing and delivery does not prepare you for the actuality of dealing with a serious health event. The practical challenges of our extremely fragmented and complex health care system make it difficult to navigate this world – even when someone is there to help the patient. And, being a caregiver is a far cry from being a health care analyst. There are many lessons to be learned for improving our system: the need for skilled co-ordination support, the need for simplifying and re-orienting the various silos of post-acute care, the importance of generating ways to support caregivers, and not least, promoting simple lessons in civility for providers of services. http://goo.gl/XjgWah

Worth Repeating

‘Supporting family caregivers at the end of life: ”They don’t know what they don’t know”‘ (p.14), in *Journal of the American Medical Association*.

Right to refuse treatment in Turkey: A diagnosis and a slightly less than modest proposal for reform

JOURNAL OF MEDICAL ETHICS | Online – 21 April 2016 – Even though there are only a few studies carried out with Turkish physicians on their attitude towards the right to refuse treatment, the author argues that recent studies on physicians’ views on informed consent and honest disclosure show that Turkish physicians do not tend to recognise their patients’ right to decline treatment. This is because the refusal of treatment crucially requires that patients be properly informed and asked for their consent before the treatment. Turkish physicians and healthcare providers’ tendency to ignore the right to decline medical treatment cannot be separated from their paternalistic approach to patients and their rights. The author argues that part of the problem is the legal framework, which, in essence, is still paternalistic. http://goo.gl/mZcsSx

Why the interdisciplinary team approach works: Insights from complexity science

JOURNAL OF PALLIATIVE MEDICINE | Online – 22 April 2016 – Although an interdisciplinary approach is considered best practice for caring for patients at the end of life, or in need of palliative care (PC) services, there is growing tension between healthcare organizations' need to contain costs and the provision of this beneficial, yet resource-intensive service. A positive team/patient experience was related to individual attributes, including self-awareness, spirit of inquiry, humility, and comfort with dying. Interdisciplinary team (IDT) attributes included shared purpose, relational coordination, holistic thinking, trust, and respect for patient autonomy. Professional and personal motivations also contributed to a positive team/patient experience. Interdisciplinary PC teams have the potential to significantly impact patient and team experiences when caring for seriously ill patients. http://goo.gl/h31VKa

Related

- *AMERICAN JOURNAL OF MEDICINE* | Online – 20 April 2016 – **'Restricting symptoms before and after admission to hospice.'** The prevalence and mean number of restricting symptoms increased progressively until about 2 months before hospice admission, before increasing precipitously to a peak around the time of hospice admission. After the start of hospice, both the prevalence and the mean number of restricting symptoms dropped markedly. http://goo.gl/aHjPo9

- *THE GERONTOLOGIST* | Online – 21 April 2016 – **'Who knew? Hospice is a business. What that means for all of us.'** Although other health care programs are regularly pilloried in the press, hospice programs are often lauded. Indeed, they sometimes appear so mission driven that one might mistake them for charities. They are not. Whether for-profit or not-for-profit enterprises, they are businesses – and concerned about their bottom line. This article highlights the implications of this business orientation for patients and providers. Methods for evaluating hospice programs nationally are critiqued. Recommendations for improving the business of hospice care are offered. http://goo.gl/02DmFt

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2016;51(4):690-696. **'Prevalence and predictors of burnout among hospice and palliative care clinicians in the U.S.'** Overall, the authors observed a burnout rate of 62% [among survey respondents], with higher rates reported by non-physician clinicians. Most burnout stemmed from emotional exhaustion, with depersonalization comprising a minor portion. Factors associated with higher rates of burnout include working in smaller organizations, working longer hours, being younger than 50 years, and working weekends. http://goo.gl/amM8OB

  N.B. Additional articles on burnout among hospice and palliative care clinicians are noted in the issue of Media Watch of 9 November 2016, #435 (pp.13-14).

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 April 2016 – **'Interdisciplinary team care and hospice team provider visit patterns during the last week of life.'** From U.S. not-for-profit hospices, 92,250 records were used of patients who died at home or in a nursing home, with a length of stay of at least seven days. On average the total number of hospice team member visits in the last week of life was 1.36 visits/day. Most were nurse visits, followed by aides, social workers, and chaplains. Visits increased over each day on average across the last week of life. http://goo.gl/dFLfjG

Rehabilitation counselor ethical considerations for end-of-life care

JOURNAL OF REHABILITATION, 2016;82(1):47-47. Among the changes in the 2010 revised Code of Professional Ethics for Rehabilitation Counselors of the [U.S.] Commission on Rehabilitation Certification (CRCC) are standards and guidelines addressing end-of-life care (EOLC) for clients who are terminally ill. The CRCC standards provide guidance in three key areas: 1) Counselor competency for working with end-of-life clients; 2) Counselor scope of practice regarding end-of-life clients; and, 3) counselor choices pertaining to confidentiality in cases where terminally ill clients are considering hastening their own deaths. In this article the authors discussed the Code ... that addresses EOLC for clients who are terminally ill. Practical ramifications of the standards are discussed and potential dilemmas presented. Practice implications for rehabilitation counselors are outlined. http://goo.gl/HVU7gF

Cont.

Noted in Media Watch, 21 July 2014, #367 (p.8):

- *BMJ CASE REPORTS* | Online – 9 July 2014 – **'The role of palliative rehabilitation in the preservation of personhood at the end of life.'** The authors highlight the impact of rehabilitative measures on efforts to preserve the personhood of a patient with metastatic renal cell carcinoma and thus maintain her dignity and quality of life and provide her with appropriate and effective holistic care at the end of life. http://goo.gl/FWPd5T

Observational evidence of for-profit delivery and inferior nursing home care: When is there enough evidence for policy change?

PLOS MEDICINE | Online – 19 April 2016 – Nursing homes, also called residential long-term care facilities or aged care homes, are regulated institutions providing around-the-clock medical and social care to (mainly) older people who are unable to live independently due to physical and/or mental disability. Because of the vulnerability of this population and frequent media reports of scandals across many industrialized countries, nursing home care quality has been a persistent focus of public concern. Inserted into the discourse on quality has been a trend in many countries to contract care to for-profit-owned facilities, and there has been considerable effort by researchers to understand the impact of for-profit ownership on care quality. The issue has particular relevance at this time as jurisdictions are challenged to care for an increasing number of very frail people over the next two decades. Even with policies to expand care at home, it is likely that many countries will require the construction of new nursing home beds. In this paper, the authors evaluate the evidence for an association between for-profit ownership and inferior care... They further frame the issue in terms of the precautionary principle, asking, "At what point is it is time to shift policy direction based on the available evidence?" http://goo.gl/sUrXPT

N.B. No mention is made by the authors of end-of-life care. ***BRA***

The patient who "must not be told": Demographic factors associated with collusion in a retrospective study in South India

POSTGRADUATE MEDICAL JOURNAL | Online – 20 April 2016 – Patients with cancer need adequate information about diagnosis, treatment options, and possible outcomes and prognosis to make therapeutic decisions. In cultures where the family plays the dominant role in healthcare decisions, doctors are often requested to collude in withholding distressing information from the patient. This challenging situation has not been well studied and there is limited knowledge on the different factors that may contribute to collusion. Collusion regarding diagnosis or prognosis is common among cancer patients referred for palliative care. In this study, it was more prevalent among female patients, manual workers, patients who had not received oncological treatment, and patients not accompanied by a spouse. http://goo.gl/jv7TXo

End-of-life care in Australia

Futility and the law: Knowledge, practice and attitudes of doctors in end-of-life care

QUT LAW REVIEW (Queensland University of Technology), 2016;16(1):54-75. Despite the potential harm to patients (and others) and the financial cost of providing futile treatment at the end of life (EOL), this practice occurs. This article reports on empirical research undertaken in Queensland that explores doctors' perceptions about the law that governs futile treatment at the EOL, and the role it plays in medical practice. The findings reveal that doctors have poor knowledge of their legal obligations and powers when making decisions about withholding or withdrawing futile treatment at the EOL; their attitudes towards the law were largely negative; and the law affected their clinical practice and had or would cause them to provide futile treatment. https://goo.gl/iihfv1

Cont.

Noted in Media Watch, 23 November 2015, #437 (p.8):

- *AUSTRALIAN HEALTH REVIEW* | Online – 16 November 2015 – **'Advance care planning in Australia: What does the law say?'** Formal documentation of wishes increases the chances that a person's wishes will be known and followed. However, one of the biggest impediments for doctors following the person's wishes is uncertainty surrounding the law, which is complicated and varies between the states and territories of Australia. http://goo.gl/Y1X5vI

Related

- *LA REVUE DE L'INFIRMIÈRE*, 2016;65(220):36-38. **'Ethical questions with patients in the palliative phase.'** Ethics question our values and the principles which govern our decisions. In the specific context of the home, where the family is alone most of the time with the sick family member, and where the team of health professionals is more fragmented, day-to-day care, notably in the palliative phase, requires almost constant ethical questioning. http://goo.gl/C48uso

  N.B. French language article.

What are the barriers faced by medical oncologists in initiating discussion of palliative care? A qualitative study in Flanders, Belgium

SUPPORTIVE CARE IN CANCER | Online – 16 April 2016 – The findings of this study provide an explanation for the possible reasons why medical oncologists feel hampered in initiating palliative care (PC) and consequently discuss it rather late in the disease trajectory. The exploration and description of these barriers may serve as a starting point for revising the medical education of oncologists. They are also a reminder to hospital management and policy makers to be aware of the impact of these barriers on the daily practice of oncology. The study identified seven heterogeneous categories of barriers which discourage oncologists from discussing PC: 1) Oncologist-related barriers; 2) Patient-related barriers; 3) Family-related barriers; 4) Barriers relating to the physician referring the patient to the medical oncologist; 5) Barriers relating to disease or treatment; 6) Institutional/organizational barriers; and, 7) Societal/policy barriers. These categories are further refined into subcategories. http://goo.gl/2yJnG9

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *INTERNATIONAL JOURNAL OF NURSING STUDENT SCHOLARSHIP*, 2016;3:Article #11. **'How is death hastening done? A review of existing sanctioned death hastening decision-making processes and practice.'** This article focuses on how assisted suicide and euthanasia have been managed in the four countries and U.S. states where it has been sanctioned and practiced. A systematic literature review and additional searches were employed to gain information on the methods, recipients, procedures, regulations, outcomes, and other information available on state-sanctioned death hastening. The findings reveal many different possible models and thus considerations required for planning in advance of death hastening actually occurring. http://goo.gl/4tjFEg

- *MEDICAL LAW REVIEW* | Online – 19 April 2016 – **'Converting the "right to life" to the "right to physician-assisted suicide and euthanasia": An analysis of *Carter v. Canada (Attorney General), Supreme Court of Canada.*'** The authors argue the Supreme Court's ... decision shows conceptual disagreements with its [1993] Rodriguez decision... Not only do these conceptual differences have little to do with the changes the Court in Carter invoked for "revisiting" Rodriguez, the Court's articulation of the sec. 7 interests, particularly the right to life, and the principles of fundamental justice, especially the principle of over breadth, are problematic on their own terms. Furthermore, the way in which the Court dealt with evidence regarding abuses in permissive jurisdictions is also subject to criticism. The authors recommend that if, as now seems inevitable, legislation is introduced, it should mandate that assisted suicide and euthanasia be performed by specially licensed non-medical personnel and only on the authorization of a Superior Court judge. They also reject the key recommendations ... by the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying.[1] http://goo.gl/9wT1Vw

  1. 'Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying: Final Report,' 30 November 2015. [Noted in Media Watch, 21 December 2015, #441 (pp.3-4)] https://goo.gl/tTeSep

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 5 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 5 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 EOL, 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/fyWe37

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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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.

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INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/0Q1Mh4

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

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

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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/5d1l9K

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

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