Canada

Misdiagnosis, death of cancer patient prompts review of indigenous health care

THE GLOBE & MAIL | Online – 27 November 2017 – The disparity between the health care offered on reserves and the services available in the rest of Canada is well documented. So is the gap in health outcomes between Indigenous people and other Canadians. It is a problem that governments at multiple levels have been grappling with for years. The federal government, which is responsible for the delivery of health care on reserves, spent $2,100 per capita for those services in 2016. That includes the cost of things not part of primary care, such as public health services. But it does not take into account the large amounts of money contributed by the provinces, which pay the bills when First Nations people need to be treated in hospitals off the reserves, among other things. So it is difficult to say exactly how money is being directed to First Nations health care, and the only way to determine whether enough is being spent is to assess the results. A 2015 Auditor-General’s report exposed significant failings in the delivery of health care on First Nations. It said not all nurses on reserves had completed mandatory training courses; that nursing stations had unaddressed health and safety issues; and that Health Canada had not assessed whether each nursing station was capable of providing essential health services. The federal government responded to that report in the most recent budget, agreeing to spend an additional $828.2 million over five years to improve health outcomes for First Nations and the Inuit. https://goo.gl/QeERVb

Auditor General of Canada
Vérificateur général du Canada


N.B. There is no mention in the Auditor General’s report of hospice or palliative and end-of-life care.

Statistics Canada

‘Aboriginal peoples in Canada: Key results from the 2016 Census,’ Statistics Canada, October 2017. [Noted in the 30 October 2017 issue of Media Watch (#536, p.2)] Download/view at: https://goo.gl/PmkRZ

Continued...
Noted in Media Watch 24 July 2017 (#522, p.14):

- **PALLIATIVE CARE: RESEARCH & TREATMENT** | Online – 21 July 2017 – ‘An analysis of journey mapping to create a palliative care pathway in a Canadian First Nations community: Implications for service integration and policy development.’ Journey mapping improves service integration and is a promising practice for First Nations communities. The implications for creating new policy to support developing culturally appropriate palliative care programs and cross-jurisdictional integration between the federal and provincial health services are discussed. **Abstract:** [https://goo.gl/27DxXm](https://goo.gl/27DxXm)

Noted in Media Watch 17 July 2017 (#521, p.13):

- **HEALTH & SOCIAL CARE IN THE COMMUNITY** | Online – 12 July 2017 – ‘Priorities and challenges for a palliative approach to care for rural indigenous populations: A scoping review.’ These included environmental and contextual issues, institutional barriers, and interpersonal dynamics challenging client/clinician interactions. Priorities: family connections throughout the dying process; building local capacity for palliative care to provide more relevant and culturally appropriate care and, flexibility and multi-sectoral partnerships to address complexities of day-to-day needs for patients/families. **Abstract:** [https://goo.gl/YKjD6p](https://goo.gl/YKjD6p)

**N.B.** Click on ‘Download article PDF’ to access the full text of the *Health & Social Care in the Community* article. Additional articles on end-of-life care for the indigenous peoples of Canada are noted in the 6 February 2017 issue of Media Watch (#498, p.1).

More long-term care beds needed to sustain aging population: Report

**THE WINNIPEG FREE PRESS** | Online – 27 November 2017 – Canada needs 43,000 new long-term care beds in the next five years if it plans to adequately care for its aging population, according to a new report...¹ Such demand will only keep growing and is expected to reach nearly 200,000 by 2035, barring any major changes to how health providers are delivering seniors’ care. That’s almost double the current number of long-term beds across the country. [https://goo.gl/WtbEiL](https://goo.gl/WtbEiL)

1. ‘Sizing Up the Challenge. Meeting the Demand for Long-Term Care in Canada,’ The Conference Board of Canada, November 2017. **Download/review at:** [https://goo.gl/RQadKY](https://goo.gl/RQadKY)

Noted in Media Watch 31 July 2017 (#523, p.8):

- **CANADIAN JOURNAL ON AGING** | Online – 27 July 2017 – ‘Broadening end-of-life comfort to improve palliative care practices in long term care.’ Findings of this study reveal that long-term care home staff, resident, and family perspectives of end-of-life comfort applied to those who were actively dying and to their families. **Abstract:** [https://goo.gl/ZhGxvo](https://goo.gl/ZhGxvo)

Noted in Media Watch 12 June 2017 (#516, p.9):

- **JOURNAL OF CANADIAN STUDIES, 2017;50(2):396-421.** ‘Intensifying relational care: The challenge of dying in long-term residential care.’ Although the culture change movement has sought to transform residential care facilities from *warehouses of death* into *homes for living*, there is growing recognition of the need to address dying within these settings. **Abstract:** [https://goo.gl/f37VGM](https://goo.gl/f37VGM)

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**Barry R. Ashpole**

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the za, 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: [https://goo.gl/jh8Mt2](https://goo.gl/jh8Mt2)
U.S.A.

Did “do not resuscitate” tattoo reflect patient’s true wish?

FLORIDA | The New York Times – 4 December 2017 – It was a scenario emergency room doctors at Jackson Memorial Hospital had discussed, but never seen in person – an unconscious patient with a tattoo across his chest that read “do not resuscitate.” The 70-year-old man at the Miami hospital posed a vexing ethical dilemma and a decision needed to be made fast. His blood pressure was dropping and he wasn’t breathing well. He had a history of chronic obstructive pulmonary disease, diabetes and he had a high blood alcohol level. “If we didn’t do something soon we were going to lose him,” said Dr. Gregory Holt, assistant professor of medicine at the University of Miami who worked on the case. In the end, the doctors followed the directions of the tattoo, but not before some hand-wringing and a quick referral to the hospital’s ethics team. Doctors immediately had two questions about the tattoo. “First, is it legal and second is it truly the man’s wishes,” Holt recalled during a telephone interview with The Associated Press. He also helped write a case study published last week…¹

https://goo.gl/KtwZ67

Specialist Publications

‘Healthcare professionals’ online use of violence metaphors for care at the end of life in the U.S.: A corpus-based comparison with the U.K.’ (p.8), in Corpora.

‘Justice in America: Ethical issues in cancer pain control’ (p.12), in Journal of Hospice & Palliative Nursing.

‘Accountability for community-based programs for the seriously ill’ (p.12), in Journal of Palliative Medicine.


Noted in Media Watch 13 March 2017 (#503, p.3):

- MAINE | The Maine Sun Journal (Augusta) – 7 March 2017 – ‘Maine lawmakers may OK “do not resuscitate” tattoos.’ A proposal before the legislature would allow Mainers who don’t want emergency medical care to get a “do not resuscitate” tattoo on their chests to indicate their wishes. The Maine Medical Association and the Maine chapter of the American College of Emergency Physicians “have substantial concern about this proposal.” https://goo.gl/a9U23A

Noted in Media Watch 1 October 2012 (#273, p.9):

- JOURNAL OF GENERAL INTERNAL MEDICINE, 2012;27(10):1383. ‘DNR tattoos: A cautionary tale.’ By imprinting the letters DNR on their body, a person obtaining a tattoo may wish to increase the certainty that their decision will be respected. Paradoxically, however, such a tattoo may exacerbate the uncertainty of emergency responders at a critical time. Abstract: https://goo.gl/VkR6ct

Straight from the patient’s mouth: Videos can clearly state your end-of-life wishes

KAISER HEALTH NEWS | Online – 30 November 2017 – Only a few U.S. organizations offer people the chance to create video testimonials, which are meant to supplement and expand upon written living wills and Physician Orders for Life Sustaining Treatment (POLST), now available in 26 states. Do-it-yourself videos are also a convenient option. One organization doing pioneering work in this field is the Institute on HealthCare Directives... Others include MyDirectives, a Texas company that helps people create digital advance directives, including personal video and audio statements; Life Messages Media of Wisconsin, which also creates video memoirs and ethical wills, a way to share your values with your family; and, In My Own Words, launched by a geriatric psychologist in California. These organizations hope the videos will help physicians and families interpret and follow written advance directives. About one-third of adults have such end-of-life documents. https://goo.gl/knwwDA

Cont.
Noted in Media Watch 20 February 2017 (#500, p.2):

- PENNSYLVANIA | The Inquirer (Philadelphia) – 16 February 2017 – ‘Doctors are confused by living wills, study finds.’ Interpreting a living will is, by definition, a life-and-death activity. So, it’s not comforting that, when hundreds of doctors were asked to decide what nine different living wills and related documents meant, they rarely agreed. In a new study,¹ the doctors reached consensus – defined as 95% agreement – on only two of the scenarios. If they read the papers and also saw a one-minute video of a patient describing his or her wishes, they agreed on how to treat a third case and reached 94% agreement on a fourth. https://goo.gl/TqJGA1


Centers for Medicare & Medicaid Services Hospice Compare site plagued with wrong information

MCKNIGHT’S LONG-TERM CARE NEWS | Online – 30 November 2017 – The Centers for Medicare & Medicaid Services’ recently launched Hospice Compare website may be giving users incorrect location information for hospice providers. The website ... quickly earned skepticism from experts for the high ratings providers were showing. Those high scores cast doubt on whether the website could be a trustworthy tool for consumers, some observers said. Now ... searching for a provider by location may turn up a list of agencies that don’t serve the ZIP code, city or state entered by a user. https://goo.gl/Bz9hHc

Noted in Media Watch 21 August 2017 (#526, p.2):

- KAISER HEALTH NEWS | Online – 18 August 2017 – ‘Medicare unveils “skeletal” site for hospice comparison shopping.’ The Centers for Medicare & Medicaid Services released Hospice Compare, a consumer-focused website that lets families compare up to three hospice agencies at a time, among 3,876 nationwide. But the measurements of quality, which are self-reported by hospices, have limited utility, some experts say. Over three-quarters of hospices scored at least 91% out of 100 on six of the seven categories, a recent paper found.¹ https://goo.gl/HbENXG


More docs specializing in nursing home care

PENNSYLVANIA | U.S. News & World Report (Philadelphia) – 28 November 2017 – More doctors in the U.S. are turning to a new clinical specialty – nursing home care. The number of physicians and health care providers concentrating on nursing home patients grew by about one-third between 2012 and 2015, researchers from the University of Pennsylvania School of Medicine found.¹ The trend is likely driven by the aging population and increased federal government oversight of nursing homes, the researchers said. “We don’t know how this trend will play out in the long term, but nursing home specialists have the potential to change the way health care is delivered in this setting,” said lead author Dr. Kira Ryskina, an assistant professor at University of Pennsylvania. “On one hand, clinicians who practice in the nursing home exclusively could improve patient outcomes and reduce costs by leveraging expertise in nursing home processes of care, for example,” Ryskina said. But concentrating patient care among nursing home specialists could also mean that patients are no longer seen by their primary care providers, who traditionally follow patients for years and across care settings. https://goo.gl/cgUCxb

Specialist Publications

‘Nursing home-hospice collaboration and end-of-life hospitalizations among dying nursing home residents’ (p.11), in Journal of the American Medical Directors Association.


Cont.
Noted in Media Watch 27 November 2017 (#540, p.3):

- CALIFORNIA | The Mercury News (San Jose) – 20 November 2017 – ‘Nursing home residents have little access to palliative care, study says.’ About 70% of nursing home residents are eligible for palliative care, but don’t get the kind of support needed to relieve their symptoms and improve their quality of life.  

  1. ‘Palliative care eligibility, symptom burden, and quality-of-life ratings in nursing home residents,’ JAMA Internal Medicine, published online 20 November 2017. Abstract: https://goo.gl/J9qd8J

  1. ‘Palliative care eligibility, symptom burden, and quality-of-life ratings in nursing home residents,’ JAMA Internal Medicine, published online 20 November 2017. Abstract: https://goo.gl/J9qd8J

  N.B. Additional articles on palliative and end-of-life care in U.S. nursing homes are noted in this issue of Media Watch.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MASSACHUSETTS | The Boston Globe – 2 December 2017 – ‘Massachusetts Medical Society ends opposition to physician-assisted suicide, adopts neutral stance.’ The Society voted to end its longstanding opposition to physician-assisted suicide and adopted a neutral stance on what it now calls “medical aid-in-dying.” The Society’s governing body approved the changes in separate votes. Delegates voted 151 to 62 to retract the policy opposing physician-assisted suicide. The provision establishing a neutral position on medical aid-in-dying passed by a margin of 152 to 56 votes. Terminology played a key role in the group’s debate over the issue. The policy that was rescinded used the term physician-assisted suicide, language that is opposed by many in favor of allowing doctors to help patients with terminal illness end their lives at the time of their choice. https://goo.gl/7zokcN

International

Northern Ireland children’s hospice faces axe due to lack of nurses

U.K. (Northern Ireland) | The Belfast Telegraph – 30 November 2017 – A children’s hospice in Northern Ireland is facing closure after struggling to recruit specialist nurses. Horizon West home in Killadeas, County Fermanagh, opened in 2012 to provide respite and palliative care to children, and requires nine paediatric nurses to operate. Most recently, 18 children and families have been using the service. The home had suspended operations, with a long-term decision on the future likely in the new year. Rosemary Barton, Ulster Unionist Member of the Legislative assembly for Fermanagh and South Tyrone, urged the Department of Health to intervene. The possible closure follows a warning this week from Northern Ireland’s health regulator Regulation & Quality Improvement Authority of a serious nursing shortage in hospitals and other community services. https://goo.gl/WLFX9k

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | ABC News (Melbourne) – 29 November 2017 – ‘Victoria becomes the first Australian state to legalise voluntary assisted dying.’ Victoria has become the first state in the country to legalise assisted dying for the terminally ill, with MPs voting to give patients the right to request a lethal drug to end their lives from mid-2019. After more than 100 hours of debate across both houses of Parliament and two demanding all-night sittings, Lower House MPs ratified the Andrews Government’s amended bill. The bill will now go to the Governor for royal assent. https://goo.gl/7c6cSq

Specialist Publications

‘Comparing doctors’ legal compliance across three Australian states for decisions whether to withhold or withdraw life-sustaining medical treatment: Does different law lead to different decisions?’ (p.6), in BMC Palliative Care.

‘An economic model of advance care planning in Australia: A cost-effective way to respect patient choice’ (p.8), in BMC Health Services Research.
Comparing doctors’ legal compliance across three Australian states for decisions whether to withhold or withdraw life-sustaining medical treatment: Does different law lead to different decisions?

BMC PALLIATIVE CARE | Online – 1 December 2017 – Despite purporting to regulate end-of-life care (EoLC), it appears law may have a limited role in decision-making by doctors. This paper considered whether variation in law across Australian states would be reflected in different decisions but found that it was not. Instead, despite very different law in Queensland compared to New South Wales (NSW) and Victoria, doctors from Queensland made broadly the same decision in the hypothetical scenario involving an advance directive, and for broadly the same reasons as did doctors in NSW and Victoria. This suggests a need for more education about the law in this area, especially where the law may differ from what may be regarded as good medical practice. These findings also have implications for health policy-makers and legislators in terms of law reform, including reconsideration of the role and utility of law in guiding decisions about the provision of EoLC. Full text: https://goo.gl/UuUzqa

Noted in Media Watch 6 June 2016 (#465, p.11):

- CRITICAL CARE & RESUSCITATION, 2016;18(2):115. ‘Knowledge of the law about withholding or withdrawing life-sustaining treatment by intensivists and other specialists.’ The authors compare the knowledge, attitudes and practice of intensivists in relation to the law about withholding or withdrawing life-sustaining treatment with six other specialties most often involved in end-of-life care. Intensivists performed better than average in legal knowledge, but important knowledge gaps remain. Intensivists had a more negative attitude to the role of law, but reported being seen as a leading source of information about legal issues by other medical specialists and nurses. Abstract: http://goo.gl/qw22hG

Noted in Media Watch 18 August 2014 (#371, p.6):

- MEDICAL JOURNAL OF AUSTRALIA, 2014;201(4):1-4. ‘Doctors’ knowledge of the law on withholding and withdrawing life-sustaining medical treatment.’ Among doctors who practise in the end-of-life field, there are some significant knowledge gaps about the law on withholding and withdrawing life-sustaining treatment from adults who lack decision-making capacity. Significant consequences for both patients and doctors can flow from a failure to comply with the law. Steps should be taken to improve doctors’ legal knowledge in this area and to harmonise the law across Australia. Abstract: https://goo.gl/FGq75b

Compassionate collaborative care: An integrative review of quality indicators in end-of-life care

BMC PALLIATIVE CARE | Online – 1 December 2017 – Compassionate collaborative care (CCC) is an emerging, complex concept. Although limited by a lack of strong empirical evidence, it is of growing importance for healthcare quality. This integrative review suggests that CCC is inextricably linked to the inherent values, needs and expectations of patients, families and healthcare providers. Communication, shared decision-making and goal setting comprise the overarching processes, while development and satisfaction are overarching outcomes. These findings may be applied to facilitate the assessment and
evaluation of existing structures, processes, and outcomes at the patient-family, team, and organizational levels, and guide the planning of team and organizational changes to achieve the essential quality indicators for CCC. Given the growing numbers of individuals who require quality end-of-life care (EoLC), this review provides a synthesis of the evidence for clinicians, administrators, and policy makers wishing to maximize the delivery of CCC in palliative and EoLC settings. **Full text:** [https://goo.gl/smV1xn](https://goo.gl/smV1xn)

**Related**

- **BMC PALLIATIVE CARE** | Online – 28 November 2017 – ‘Enhancing integrated palliative care: what models are appropriate? A cross-case analysis.’ In this longitudinal organisational case study, a complex picture of hospice integration in the U.K. emerged highlighting the needs of patients with non-cancer diagnoses and multi-morbidities. This means that greater integration by hospices is required to work with, rather than replace, local providers, with more clarity in managing cross-organisational information sharing and allocation of co-ordination roles and responsibilities. Priorities for integrated working include a single information system and a skilled named professional to coordinate care and form meaningful relationships. **Full text:** [https://goo.gl/hz6xhw](https://goo.gl/hz6xhw)

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

**Challenges to discussing palliative care with people experiencing homelessness: A qualitative study**

**BMJ OPEN** | Online – 28 November 2017 – This is the largest U.K. study exploring views and experiences of people experiencing homelessness and those supporting them regarding palliative care (PC) conversations. While all participants were service users or providers in London, the challenges described and the strategy suggested for managing uncertainty could be beneficial in other locations. Methods for providing PC support for people who are homeless need urgent consideration. The lack of facilities that can provide adequate support to people who are homeless with high support needs demonstrates the need to strengthen and foster collaborations between partners from health, housing, social, homelessness and PC services. Also, given the uncertainties in supporting people who are homeless and experiencing advanced ill health, the authors propose parallel planning as a method for identifying, exploring and respecting the wishes of individuals as their health deteriorates. For some people, moving the focus of conversations away from “recovery” towards “living well/quality of life” has the potential to facilitate more patient-centred, multidisciplinary care and contingency planning. Future research is needed to explore the viability of this approach and evaluate its effectiveness. It is essential that all professional groups are provided with training and support (potentially from PC services) to bring about this shift in thinking, and that robust evaluation of this training is completed. **Full text:** [https://goo.gl/9oym5b](https://goo.gl/9oym5b)

Noted in Media Watch 6 November 2017 (#537, p.5):

- U.K. (England) | Care Quality Commission – 31 October 2017 – ‘A second class ending: End-of-life care for people who are homeless.’ The Commission co-produced this discussion paper with the Faculty for Homeless & Inclusion Health, an independent, multi-disciplinary body focused on the health care of homeless people. **Download/view at:** [https://goo.gl/5aygwT](https://goo.gl/5aygwT)

Noted in Media Watch 10 July 2017 (#520, p.5):


1. ‘End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care,’ Palliative Medicine, published online 3 July 2017. **Full text:** [https://goo.gl/b3eQ42](https://goo.gl/b3eQ42)
Healthcare professionals’ online use of violence metaphors for care at the end of life in the U.S.: A corpus-based comparison with the U.K.

CORPORA, 2017;12(1):55-84. The use of violence metaphors in healthcare has long been criticised as detrimental to patients. Recent work ... has combined qualitative analysis with corpus-based quantitative methods to analyse the frequency and variety of violence metaphors in the language of U.K.-based patients, family carers and healthcare professionals talking about cancer and/or end-of-life care (EoLC). A new 250,324-word corpus of U.S. health professionals’ online discourse has been collected to add a contrastive, cross-cultural element to the study of metaphors in EoLC. The authors discuss the most over-used and under-used semantic domains in the U.S. corpus as compared with the pre-existing U.K. corpus of online healthcare professional discourse. Second, they show that there are no notable frequency differences in the occurrence of violence metaphors in the two corpora, but we point out some differences in the topics that these metaphors are used to discuss. Third, the authors introduce a novel framework for analysing agency in violence metaphors and apply it to the U.S. corpus. This reveals the variety of relationships, concerns and challenges that these metaphors can express.

Noted in Media Watch 15 May 2017 (#512, p.10):

- **ONCOLOGY NURSING NEWS** | Online – 6 May 2017 – ‘Battle weary: When discussing cancer, military terminology doesn’t help.’ Promotions for cancer centers or fundraisers, as well as conversations between patients and their healthcare providers or loved ones, often focus on the idea of “fighting” or “battling” cancer. But how do these military metaphors ... affect the outlook and coping ability of patients? And what do they accomplish when it comes to motivating those without cancer to engage in preventive measures? **Full text:** https://goo.gl/tHjC7s

Noted in Media Watch 17 October 2016 (#483, p.14):

- **MEDICAL HUMANITIES** | Online – 5 October 2016 – ‘Employing imaginative rationality: Using metaphor when discussing death.’ Skilful use of imaginative rationality in the healthcare setting may illuminate the elusive and often eschewed topic of death in a way that fosters clarity and new understandings and pave the way towards a better life and death for patients. By becoming aware of the nuances contained within patients’ – as well as their own – metaphors, clinicians may enhance patients’ overall healthcare experience and avert miscommunication. **Abstract:** https://goo.gl/FIWROc

Refusing treatment prior to becoming incapacitated: Supported decision-making as an approach in advance directives

EUROPEAN JOURNAL OF HEALTH LAW | Online – 21 November 2017 – While the normative logic behind advance directives (ADs) remain straightforward, as instruments of law they are not always effective because of questions about their validity and applicability. It is on this basis that this article attempts to resolve the legal intricacies on ADs refusing treatment prior to becoming incapacitated. The author advances a thesis in support of a modification of an approach known as supported decision-making to facilitate people in making ADs. This approach pre-empts most of the doubts about an ADs’ validity. The argument is founded on the presumption that an AD made using the supported decision-making approach provides a higher degree of assurance about the circumstances surrounding the making of ADs, rendering it more likely to be binding on healthcare professionals. **Abstract:** https://goo.gl/r15rMj

Related

- **BMC HEALTH SERVICES RESEARCH** | Online – 1 December 2017 – ‘An economic model of advance care planning in Australia: a cost-effective way to respect patient choice.’ The results showed that, compared to usual care, a nationwide advance care planning (ACP) program for people aged 65+ years who were at risk of dementia would be cost-effective. However, the results only hold if ACP completion is higher than 50% and adherence to ACP wishes is above 75%. The result is largely driven by providing treatment and care consistent with patient ACP preferences, leading to fewer hospitalisations and less-intensive care at end-of-life. **Full text:** https://goo.gl/yGU985

Cont.
End-of-life care: Care Quality Commission briefing

GP | Online – 29 November 2017 – Care of people at the end of life (EoL) falls under the question of whether services are effective – one of five key questions used by Care Quality Commission (CQC) inspectors. Key line of enquiry asks: “Do people, including those in the last 12 months of life, have their needs assessed and their care planned and delivered in line with evidence based guidance practice?” Approximately half a million people die in England each year, two-thirds of whom are over 75 years old. This number will increase as our population ages. GPs play a vital role in coordinating and overseeing patients’ EoL care, and caring for their loved ones after they have gone. Every person deserves good care at the end of their life. This means that people should be treated with dignity and respect and, where possible, in their preferred place of care. However, we do not always get it right: access to and quality of care for people at the EoL remains variable, especially for those with a non-cancer diagnosis. Although most people would prefer to die at home, over half are still dying in hospital. GPs are in the position of being able to identify when patients are at the end of their life and have the difficult but necessary conversations about death with them, building on their long-established trusting relationship with them and their families. How GP practices provide EoL care to their patients is likely to come up during a CQC inspection. Full text: https://goo.gl/fJAEpi

Five priorities for care of the dying person

 Recognition: the possibility that a person may die within the coming days or hours is recognised and communicated clearly, decisions about care are made in accordance with the person’s needs and wishes, and these are reviewed and revised regularly.

 Communication: sensitive communication takes place between staff and the person who is dying and those important to them.

 Patient involvement: the dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

 Family needs: the needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

 Tailored care planning: an individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

 Cont. next page

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.16.
Noted in Media Watch 5 June 2017 (#515, p.10):

- **GP** | Online – 30 May 2017 – ‘**Palliative care: How GPs can handle conversations about end-of-life care.**’ A new report explores the taboo around death, and included the worrying revelation that while 76% of people with cancer have thought about their own death, just 8% of these have shared their feelings with a healthcare professional. GPs and their teams have the potential to play a significant role in helping people work through an advance care plan. When healthcare professionals have a record of where someone would like to die, they are nearly twice as likely to die in the place of their choosing. **Full text:** [https://goo.gl/g5e2jr](https://goo.gl/g5e2jr)


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**Does research improve clinical care?**

*THE HIPPOCRATIC POST* | Online – 28 November 2017 – We can think of the research process as a pipeline, that starts with the question of interest, and ends up with a change in clinical practice. A landmark paper published ... in 2014 showed that this pipeline is dramatically and inherently leaky. Of the billions invested each year in biomedical research, the authors estimated that a staggering 85% may be wasted: it never has a chance of improving patient care. These leaks occur at five main stages: 1) Because the wrong question is asked; 2) Because the wrong methods are used; 3) Through inefficient and burdensome regulation; 4) Through incomplete publication of research findings; and, 5) Because published research findings are not usable in practice. The importance of research in improving the quality of end-of-life care we provide was recognised by Dame Cicely Saunders, the founder of the modern hospice movement, who pioneered research in the 1960s into the safety of opioids (such as morphine) for people close to death. The volume of research carried out in palliative care has increased since Cicely Saunders' pioneering studies, but what do we know about its value? Let’s consider the first leak in the pipeline: what constitutes the wrong research question? Aren’t all research questions of value? The answer, sadly, is no. If a research question is asked, to which there is already a reliable answer, then repeating this study is of little benefit to patients. Similarly, if a research question is considered of little importance to patient and families, then resources would arguably be better spent elsewhere. And of course, asking low priority research questions means that high priority questions may be ignored. This was illustrated by the Neuberger Review into the Liverpool Care Pathway which showed the terrible consequences of national policies that are not backed up by appropriate evidence from research. Full text: [https://goo.gl/kzqVsR](https://goo.gl/kzqVsR)

1. ‘Reducing waste from incomplete or unusable reports of biomedical research,’ *The Lancet*, 2014; 383(9913):267-276. **Summary:** [https://goo.gl/yHnfoD](https://goo.gl/yHnfoD)


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Noted in Media Watch 20 November 2017 (#539, p.9):

- **ANNALS OF INTERNAL MEDICINE** | Online – 14 November 2017 – ‘**A research agenda for high-value palliative care.**’ Because demand has quickly outstripped the supply of palliative care (PC) specialists, the field’s ability to sustainably provide high-value care is paradoxically threatened by its own success. The authors propose a research agenda organized around five key questions on the optimal organization and allocation of limited resources in specialty PC to close the gap between the workforce and patient need. **Abstract:** [https://goo.gl/ZbDzx2](https://goo.gl/ZbDzx2)
What influences palliative care nurses in their choice to engage in or decline clinical supervision?

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2017;23(11):524-533. Clinical supervision (CS) has been around since the early 1990s in the U.K. and has been endorsed by government and professional bodies. Levels of engagement range from 18% to 85%. Palliative care (PC) nurses all used informal team support for “in the moment” support. Some engaged in formal CS to reflect “on action” and to challenge practice. Nurses reported a lack of clarity regarding CS, but once this was overcome and engagement with CS was established it led to changes in practice, identification of training needs and team building. The option of choice between group and individual supervision was found to be important. Group supervision led to enhanced understanding of group members which also led to team building, individual sessions were useful for individual issues. Protected time was essential for staff to be able to engage in CS. Staff who worked in larger teams reported higher levels of engagement, whereas a small team reported less need due to more informal team support. These findings illuminate the importance of choice for support. Nurses need to be aware of their options for support and ultimately how this support affects the care they provide. The Palliative Care Nurse’s Model of Support was developed, which shows the effects of each choice and how this may lead to team-building. Abstract: https://goo.gl/9d6Hdo

Communication disorders in palliative care: Investigating the views, attitudes and beliefs of speech and language therapists

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2017;23(11):543-551. Speech and language therapists (SLTs) provide intervention for communication and swallowing to patients with life-limiting conditions, such as dementia and head and neck cancer. The role of the SLT in palliative care (PC) is difficult to define. Much is known about the clinical aspects of this role; however, little is known about the core values, beliefs and expectations of SLTs working in this sector, particularly with regard to their role in supporting patients’ communication. This report aims to form a picture of the experiences and views of SLTs about their communication role in PC. Results of this study suggest that SLTs are forging a self-identity in a sector that is itself constantly evolving, which causes difficulties in defining their role. Participants report that other health professionals have a poor understanding of the SLT’s role. SLTs may benefit from PC-specific guidelines and increased interprofessional awareness of their role in order to become better integrated into the PC sector. Abstract: https://goo.gl/rKnPw7

Nursing home-hospice collaboration and end-of-life hospitalizations among dying nursing home residents

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 28 November 2017 – The potential benefits of nursing home-hospice collaboration may vary with the patterns of this collaboration. This study examined the relationship between the attributes of collaboration ... and end of life (EoL) hospitalizations among dying nursing home (NH) residents. The pattern of collaboration has changed significantly over years; the average number of hospices in a NH increased from 1.4 in 2000 to 3.2 in 2009. The volume of collaboration also increased substantially. Having more hospice providers in the NH was not associated with lower risks of EoL hospitalizations. After accounting for individual and facility characteristics, increasing hospice providers from 1 to at least 4 was associated with an overall 1 percentage point increase in the likelihood of EoL hospitalizations among dying residents, and such relationship remained in NHs with moderate or high volume NHs in the stratified analyses. Stratified analysis by rural versus urban NHs suggested that the relationship between the number of hospice providers and EoL hospitalizations was mainly in urban NHs. Abstract: https://goo.gl/B4kWUM
Justice in America: Ethical issues in cancer pain control

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2017;19(6):508-513. Pain is common in those with a life-threatening illness, yet barriers to adequate treatment persist. New challenges add to the well-known barriers of limited education, lack of time, and impaired access to expert treatment. The opioid abuse epidemic and the rising rate of deaths related to misuse of opioids present new obstacles to cancer pain relief. Although many of the efforts to reduce the impact of the opioid epidemic are important to the community, there are unintended consequences. When facing these challenges, ethical principles serve as a guide to the provision of safe and effective pain control in hospice and palliative care. The ethical principle most challenged during our current state is justice, the equal and fair distribution of resources. There are numerous examples of unfair distribution of cancer pain treatment, notably limited access to pharmacologic and non-pharmacologic therapies. Hospice and palliative nurses who are dedicated to the provision of excellent cancer pain care can ensure equitable distribution of resources, including opioids. Solutions to the challenge of fair access include individual professional development, interventions by health care organizations, and action by professional organizations. Abstract: https://goo.gl/tjPzys

Noted in Media Watch 13 November 2017 (#538, p.9):

- CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 6 November 2017 – ‘Appeal to physicians – opioids have their place. Let’s avoid an unintended tragedy.’ A well-known tragedy has occurred with respect to opioids – the crisis of overdose deaths from opioids that were obtained from various legitimate and illegitimate sources. This has necessitated urgent government and public action. A second, preventable tragedy is beginning to occur as an unintended consequence of the first. Full text: https://goo.gl/VzahC4

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

Accountability for community-based programs for the seriously ill

JOURNAL OF PALLIATIVE MEDICINE | Online – Accessed 4 December 2017 – Innovation is needed to improve care of the seriously ill, and there are important opportunities as we transition from a volume- to value-based payment system. Not all seriously ill are dying; some recover, while others are persistently functionally impaired. While we innovate in service delivery and payment models for the seriously ill, it is important that we concurrently develop accountability that ensures a focus on high-quality care rather than narrowly focusing on cost containment. The Gordon and Betty Moore Foundation convened a meeting of 45 experts to arrive at guiding principles for measurement, create a starter measurement set, specify a proposed definition of the denominator and its refinement, and identify research priorities for future implementation of the accountability system. A series of articles written by experts provided the basis for debate and guidance in formulating a path forward to develop an accountability system for community-based programs for the seriously ill, outlined in this article. As we innovate in existing population-based payment programs such as Medicare Advantage and develop new alternative payment models, it is important and urgent that we develop the foundation for accountability along with actionable measures so that the healthcare system ensures high-quality person- and family-centered care for persons who are seriously ill. Full text: https://goo.gl/gfDWhE

Sharing end-of-life care preferences with family members: Who has the discussion and who does not

JOURNAL OF PALLIATIVE MEDICINE | Online – 30 November 2017 – Four themes emerged in this study: 1) Being proactive or passive/reactive; 2) Perceiving discussion of death as normal or abnormal; 3) Response to family resistance/disconnection; and, 4) Knowledge acquired. A fifth theme, the role of healthcare providers in family end-of-life care (EoLC) discussions, resulted from facilitators’ questions. Theme examination led to identification of a central category, decision-making. It is important to understand the differing experiences and attitudes of those who do or do not engage in end-of-life discussions. Research is needed on healthcare practitioners’ use of decision-making tools to help patients discuss their EoLC preferences with family and others, the goal of which is to provide care consistent with patients’ goals. Abstract: https://goo.gl/eHJsiw
Bereavement challenges and their relationship to physical and psychological adjustment to loss

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 November 2017 – The psychosocial challenges confronted by bereaved survivors may contribute to poor bereavement adjustment. This study is a preliminary examination of the factor structure of a new measure of bereavement challenges and their relationships to quality of life and mental illness in bereaved cancer caregivers. This measure was designed to identify intervention targets to reduce the likelihood of prolonged grief. A factor analysis identified five factors: 1) Challenges with connecting with others; 2) Challenges with change; 3) Challenges imagining a hopeful future; 4) Challenges with accepting the loss; and, 5) Challenges with guilt. Greater endorsement of bereavement challenges was associated with worse quality of life, more severe symptoms of prolonged grief, and greater likelihood of meeting criteria for a mental disorder. Assessing the challenges associated with bereavement is important to understanding barriers to bereaved individuals’ adjustment. The five factors identified point to potential targets for clinical intervention. Abstract: https://goo.gl/AB7fVx

How do healthcare practitioners talk about end-of-life conversations? A poetic inquiry

JOURNAL OF RESEARCH IN NURSING | Online – 29 November 2017 – Despite agreement that end-of-life (EoL) conversations should happen early on in the illness trajectory, it is widely acknowledged that healthcare practitioners often engage in these conversations when death is imminent or avoid the conversation altogether. Healthcare practitioners’ feelings of distress influence how EoL conversations are approached, yet thorough exploration of this emotional experience and its impact are largely missing from the literature. The aims of this preliminary scoping literature review using poetic inquiry were to examine physicians’ and nurses’ emotional distress in their accounts of how they approach EoL conversations, and to map key concepts relevant to exploring barriers to these conversations. The poetic findings highlight the differing nature of distress for physicians and nurses. Physicians’ distress appears to stem from adhering to their role of “curer” when communicating with terminally ill adult patients at the EoL, whereas the sources of nurses’ distress appear to be interprofessional hierarchies and conflicts. Abstract: https://goo.gl/YWnYJh

What do humanitarian emergency organizations do about palliative care? A systematic review

MEDICINE, CONFLICT & SURVIVAL | Online – 4 December 2017 – Humanitarian emergency organizations have only recently integrated care for non-communicable diseases into their relief action. The needs for palliative care (PC) in emergencies are still largely unmet. A systematic review was undertaken of health programmes run by international humanitarian organizations that take palliative care and/or enhanced pain control into account. Electronic databases were searched for publications of health programmes providing PC and/or enhanced pain control in emergency situations. Health departments of major international organizations and experts were contacted for relevant information. One publication on pain treatment in amputees in Freetown, Sierra Leone, fulfilled the selection criteria. International humanitarian organizations shared information on their programmes in the Democratic Republic of the Congo, Haiti, Kenya and Ukraine/Russia. There is very little information available on PC and/or enhanced pain control in emergency settings. First programmes have just been initiated in the field. More emphasis on sharing experiences and publication could accelerate a broader integration of PC into humanitarian programmes. Abstract: https://goo.gl/7dahXr

Noted in Media Watch 22 May 2017 (#513, p.19):

- PREHOSPITAL & DISASTER MEDICINE | Online – 20 April 2017 – ‘Aid – When there is “nothing left to offer”: A survey and qualitative study of ethics and palliative care during international humanitarian emergencies.’ There is a lack of evidence clarifying ethical and practical possibilities and consequences of humanitarian organizations, addressing or failing to address patients’ palliative needs. This study seeks to inform realistic, context-sensitive guidance, education, and practice for the provision of palliative care during humanitarian emergencies. Abstract: https://goo.gl/CPrrGF

N.B. Additional articles on the provision of palliative care during humanitarian emergencies are noted in the issue of Media Watch.
Poll: Half of doctors, nurses have put off giving bad news

MEDSCAPE MEDICAL NEWS | Online – 29 November 2017 – Half of physicians (i.e., survey respondents) and more than two in five nurses and advance practice nurses say they have delayed giving bad news to patients, according to a Medscape Medical News poll. The poll question was one of four pitched to readers ... after Medscape contributor and New York University medical ethicist Art Caplan wrote a commentary in which he posed questions about whether physicians should get to decide the best timing for delivering bad health news and whether they should be punished if failure to disclose results in worsening of the condition. Full text: https://goo.gl/BxpkEE


A toolkit for enhancing end-of-life care: An examination of implementation and impact

THE PRISON JOURNAL | Online – 28 November 2017 – The purpose of this study was to examine the infusion of a Toolkit for Enhancing End-of-Life Care in prisons, as well as the outcome and impact on the quality of prison end-of-life care. A total of 74 front-line staff and administrators were in attendance across two post-Toolkit-infusion evaluation visits. Applying qualitative analysis, co-researcher outcome findings were related to activities, community outreach and relations, multidisciplinary team, quality improvement approach, and participatory action research team effects. Organizational outcomes included barriers and challenges, cost, organizational features, sphere of influence, readiness (for change), and sustainability. Abstract: https://goo.gl/RR72ni

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 November 2017) can be downloaded/viewed at Palliative Care Network-e: https://goo.gl/YLckx6

Trust, intent, authenticity, and good dying: Beyond the autonomy debates and towards a philosophy of palliative care

PROGRESS IN PALLIATIVE CARE | Online – 26 November 2017 – At a time when death-and-dying are increasingly thought of as medical events, even to the point where professionals traditionally oriented towards healing are sometimes thought to be responsible for intentionally ending the lives of patients, it is becoming increasingly clear that palliative care (PC) is both unique and critically important. In this article, the author shows the need for clear articulation of the philosophy of this distinctive practice that properly acts with intent towards neither health in a narrowly medical sense nor patient death. He proposes four lenses through which a rigorous philosophy of PC may be approached: trust, intent, authenticity, and the foundational question of good dying – literally euthanasia. The author contends that proper PC seeks to cloak (palliare) pain within the context of trusting relationships both as a good in itself and as way of de-cloaking the things that form important components of most people’s narratives of good dying: opportunities to authentically engage with trusted others with the aim of finding some kind of meaning in life and community, even during the process of dying. Furthermore, PC is characterized by a non-paternalistic willingness to point outside of itself in order to help patients authentically engage the important existential questions of human mortality via lenses that extend beyond those offered by scientific medicine. Abstract: https://goo.gl/t3AnxB
Assisted (or facilitated) death

Representative sample of recent journal articles:

- SOMATECHNICS, 2017;7(2):201-217. ‘The Somatechnologies of Canada’s Medical Assistance in Dying law: LGBTQ discourses on suicide and the injunction to live.’ In June 2016, the Canadian government passed Bill C-14 on medical assistance in dying (MAiD), allowing for medically assisted suicide when “death has become reasonably foreseeable.” While available for ill or physically disabled people at the end-of-life, medically assisted suicide is denied in cases where people are perceived to have a mental disability and whose suffering is strictly emotional/psychological, such as suicidal people. The author argues that this distinction results in constructing two classes of suicidal subjects by considering physically disabled or ill people as legitimate subjects who should receive assistance in dying and suicidal people as illegitimate subjects who must be kept alive through what the author calls the “injunction to live” and “somatechnologies of life.” Analysing discourses on suicide targeting lesbian, gay, bisexual, trans and queer (LGBTQ) people in LGBTQ scholarship, he argues that, based on the silencing of suicidal subjects through the injunction to live, suicidal people constitute an oppressed group whose claims remain unintelligible within society, law, medical/psychiatric systems and LGBTQ scholarship. This article calls for listening to suicidal people’s voices and developing an accountable response to their suffering and claims. Abstract: [https://goo.gl/UCbpUZ](https://goo.gl/UCbpUZ)

Journal Watch

The perils of predatory publishing: Views and advice from an editor and a health sciences librarian

PAIN MANAGEMENT NURSING, 2017;18(6):351-352. In the last ten years scholarly publishing has experienced a significant transformation due in part to increased internet access. In the past, articles were primarily available in print form only, but now there are journals solely published online. With the new open-access model, more articles from all disciplines are now freely available through the Internet and not restricted by subscriptions that limit access. Predatory publishers often exhibit questionable practices with a major incentive to collect fees from authors for publishing their articles. Those most at risk are newer authors who are not familiar with this practice. A bigger concern is how predatory publishers are affecting the science that underpins our practice and decision-making. We assume that published articles are of high quality and based on good scholarship/scientific methods. Unfortunately this may not always be true. Professionals in all disciplines need to and be aware of predatory publishers and wary of what they are reading. Full text: [https://goo.gl/Cbf9NV](https://goo.gl/Cbf9NV)

Media Watch: Editorial Practice

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

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2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
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: https://goo.gl/ePyoE!
INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://goo.gl/frPgZ5
PALLIATIVE CARE NETWORK-e: http://goo.gl/8JyLmE
PALLIMED: http://goo.gl/7mrgMQ
[Scroll down to ‘Aggregators’ and ‘Media Watch by Barry Ashpole’]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: https://goo.gl/psUfub
[Scroll down to ‘Resource Collection’]
SINGAPORE | Centre for Biomedical Ethics (CENTRES): https://goo.gl/UZTPVU

Canada

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: https://goo.gl/BLgxy2
[Scroll down to ‘Are you aware of Media Watch?’]
ONTARIO | Acclaim Health (Palliative Care Consultation): https://goo.gl/wGi7BD
[Scroll down to ‘Additional Resources’]
ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/IOSNC7
ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYc
[Scroll down to ‘International Palliative Care Resource Center hosts Media Watch’]

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: https://goo.gl/LeTFXU
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HUNGARY | Magyar Hospice Alapítvány: https://goo.gl/vgkX45
U.K. | Omega, the National Association for End-of-Life Care: http://goo.gl/UfSZtu

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