

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.

7 May 2018 Edition | Issue #562



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Economics of palliative care: Scroll down to [Specialist Publications](#) and ‘Prompt palliative care saves money, especially in sickest patients’ (p.14), in *MedPage Today*.

Canada

Palliative care inadequate for coming “silver tsunami” concludes Hamilton report

ONTARIO | *The Hamilton Spectator* – 2 May 2018 – Significant gaps in end-of-life care (EoLC) were found in a case study of Hamilton that concludes current infrastructure is inadequate to handle the palliative care needs of the “silver tsunami” of baby boomers drawing near.¹ The hospital remains the most common place where people die in the Hamilton Niagara Haldimand Brant Local Health Integration Network, reveals a report by Hamilton think tank and charity Cardus. “In Hamilton there is still a significant gap between what we need and what we have,” concludes Cardus senior researcher Doug Sikkema in the case study. “In many ways, then, Hamilton seems to present a case in point of the national narrative.” Two in five area deaths took place in acute care from 1 April 2012 to 31 March 2013, reports Cardus Health, which researches Canadian EoLC.² Of those, 95% were palliative patients, as opposed to those dying from significant trauma or injury.

Four out of five were seniors and the vast majority were admitted through the emergency department. Most worrisome is that 15% of the patients who died in hospital were transferred from long-term care and three-quarters were living at home prior to being admitted to acute care. <https://goo.gl/6RGwxy>

Specialist Publications

‘Compassionate communities in Canada: It is everyone’s responsibility’ (p.8), in *Annals of Palliative Medicine*.

‘Developing palliative care programs in Indigenous communities using participatory action research: A Canadian application of the public health approach to palliative care’ (p.8), in *Annals of Palliative Medicine*.

1. ‘Case study: Hamilton,’ Cardus, April 2018. **Download/view at:** <https://goo.gl/iGvh83>

2. ‘Renewing end-of-life,’ Cardus, April 2018. **Download/view at:** <https://goo.gl/N4jdXF>

N.B. The Ontario Auditor General’s 2017 report, noted in the 11 December 2017 issue of Media Watch (#542, p.1), includes discussion/evaluation of the provision and delivery of palliative care in the province, and can be downloaded/viewed at: <https://goo.gl/XUmEGi>. And, in June 2016, Health Quality Ontario published ‘Palliative Care at the End of Life,’ noted in the 4 July 2016 issue of Media Watch (#469, p.2), which can be downloaded/viewed at: <http://goo.gl/GW0Xh9>

Ontario to plug gap in home-care coverage for patients who move provinces

ONTARIO | *The Globe & Mail* (Toronto) – 1 May 2018 – The Ontario [provincial] government is closing a gap in medicare that temporarily denies home-care coverage to Canadians who relocate from other provinces, including terminally ill patients who are not expected to live past the three-month waiting period for an Ontario Health Insurance Plan card. The province's Liberal government ... is making the move 18 months after an New Democratic Party Member of the Provincial Parliament tabled a private member's bill in memory of Dan Duma, a Windsor, Ontario, man who was refused publicly funded home care after he returned to his hometown from a job in Alberta. Mr. Duma died of liver cancer at the age of 48 in July 2016. His final wish was to die at home, but that was not possible without the help of nurses, personal-support workers and medical equipment to ease his end-of-life suffering. In the end, a doctor bent the rules to secure a bed for Mr. Duma at a hospice... Hospice services are subject to the same three-month waiting period as home-care services. <https://goo.gl/HcJH1y>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEWFOUNDLAND & LABRADOR | CBC News (St. John's) – 1 May 2018 – **'Why are there fewer doctor-assisted deaths in Newfoundland? It might have to do with religion.'** Newfoundland & Labrador may have one of the oldest and unhealthiest populations in Canada, but when it comes to medical assistance in dying the rates are well below the Canadian average. Stiff opposition from religious groups is one factor, with some denominations refusing to allow doctor-assisted deaths at publicly-funded, faith-based nursing homes, except under extreme circumstances <https://goo.gl/3hni5U>

U.S.A.

Supporting the patient journey: The role of palliative care in pediatrics

U.S. NEWS & WORLD REPORT | Online – 4 May 2018 – Since the 1960s when the hospice movement really began, we have been slowly changing our approach to management of chronic illness. While the stimulus for hospice medicine, dying in comfort and with dignity, has stayed constant since that time, the where and how have evolved significantly. And with the addition of palliative care (PC), a defined medical specialty since 2006, we have been able to take the lessons learned in that nearly 60 years of hospice experience and apply them to not only the terminally ill but also for chronic disease management. So while it seems clear that the expertise of our pediatric PC specialists is hugely beneficial to our child patients, very few actually get the benefit of their care. This is due in part to the paucity of these providers nationwide. According to pediatric board certification data, slightly less than 250 PC providers are focused on serving children in the U.S. Obviously, this represents a significant gap when considering that 27% of our U.S. children suffer from chronic illness and 53,000 die per year. In addition, it's been culturally difficult for both the

health care systems and society to shift the focus from cure to symptom management. This delays some of the requests for PC consults and then it may be too late in the course to realize all the benefits the child may have received. <https://goo.gl/GVQh2y>

Specialist Publications

'Pediatric palliative care and the pediatric intensive care unit' (p.10), in *Current Pediatrics Reports*.

'Integrative therapies to support pediatric palliative care: The current evidence' (p.10), in *Current Pediatrics Reports*.

'Impact of natural disasters on children receiving palliative care lessons learned from Hurricane Harvey' (p.11), in *Current Pediatrics Reports*.

'Benefits of early referral to pediatric palliative care for a child with a rare disease' (p.11), in *Pediatrics*.

An advance directive for patients with dementia

THE NEW YORK TIMES | Online – 30 April 2018 – Advance directives typically do not cover a likely scenario for one of the leading causes of death in this country: dementia. Missing in standard documents, for example, are specific instructions about providing food and drink by hand as opposed to through a tube. Advanced dementia, including Alzheimer's disease, is the sixth leading cause of death overall in the U.S. It is the fifth leading cause for people over 65, and the third for those over 85. Yet once the disease approaches its terminal stages, patients are unable to communicate their desires for or against life-prolonging therapies, some of which can actually make their last days more painful and hasten their demise. Unlike those with terminal cancer or amyotrophic lateral sclerosis, diseases in which cognitive function usually remains intact, people in an advanced stage of a dementing illness cannot determine and effectively communicate what they do and do not want done for them. <https://goo.gl/c5QyJy>

Noted in Media Watch 9 April 2018 (#558, p.9):

- *AGING & MENTAL HEALTH* | Online – 2 April 2018 – ‘**Exploring provider-surrogate communication during Physician Orders for Life-Sustaining Treatment discussions for individuals with advanced dementia.**’ Study participants demonstrated emotional support by valuing what the surrogate said, acknowledging the surrogate's emotions, listening carefully, understanding the patient as a person, and eliciting questions. However, care providers rarely conveyed comprehensive information about the patient's current condition and end-of-life treatment options. **Abstract:** <https://goo.gl/e733Xt>

Noted in Media Watch 26 February 2018 (#552, p.12):

- *BMC MEDICAL ETHICS* | Online – 20 February 2018 – ‘**Advance directives as a tool to respect patients' values and preferences: Discussion on the case of Alzheimer's disease.**’ Few and not conclusive data exist on the potential positive impact of advanced directives on the treatment of patients with severe cognitive impairment or dementia. This requires concrete policies and actions to make directives known and effective, particularly in a context of increased possibility of early diagnosis of Alzheimer's disease paired with lack of effective treatments. **Full text:** <https://goo.gl/iUAV3j>

Grants to tackle a difficult – but unavoidable – issue: End-of-life care

INSIDE PHILANTHROPY | Online – Accessed 29 April 2018 – Remember those “death panels” that supposedly were part of Obamacare and a big government plot to let bureaucrats pull the plug on grandma? We haven't heard much about that canard lately, even though the Affordable Care Action (ACA) has now been up and running for a while. But that's not to say the dilemmas of end-of-life care (EoLC) aren't on the minds of healthcare experts in Washington DC and beyond. A grant-making outfit called the Patient-Centered Outcomes Research Institute – which was created as part of the ACA, with funding from both Congress and insurers – is actively wrestling with these issues. There's only a limited number of funders who engage the topic of EoLC, despite how important it is. Last year, it was reported that the Community Foundation for Southern Arizona and the David & Lura Lovell Foundation were investing nearly \$3 million

Specialist Publications

‘**Addressing palliative and end-of-life care needs with Native American elders**’ (p.12), in *International Journal of Palliative Nursing*.

‘**Association between hospice length of stay, health care utilization, and Medicare costs at the end of life among patients who received maintenance hemodialysis**’ (p.12), in *JAMA Internal*

‘**Disparities in access to palliative medication: The duty of the state to ensure opioid medication access**’ (p.16), in *Penn Bioethics Journal*.

“‘**I don't want to die, but I am dying**”: **Re-examining physician-assisted suicide in a new age of substantive due process**’ (p.17), in *Arizona Law Review*.

‘**Physician-assisted suicide: Why neutrality by organized medicine is neither neutral nor appropriate**’ (p.17), in *Journal of General Internal Medicine*.

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in this area. Another funder paying attention is the Gordon & Betty Moore Foundation, which is addressing end-of-life issues through its Serious Illness Care initiative. Moore, along with other funders, including the John A. Hartford Foundation, has been involved in efforts to advance the recommendations made in a 2015 report by the Institute of Medicine...¹ The Cambia Health Foundation is another grant-maker interested in this area. The Robert Wood Johnson Foundation (RWJF) used to be an important funder of work on end-of-life issues, but it wound down that grant-making a while ago. Here and there, though, you'll see RWJF money supporting such work, like its support for a report on EoLC published by the Aspen Institute Health Strategy Group.² The scarce attention to EoLC issues reflects a broader shortcoming of philanthropy, which is that aging is not a popular focus for foundations. <https://goo.gl/41uWN8>

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in the 22 September 2014 issue of Media Watch (#376, p.4)] **Download/view at:** <http://goo.gl/mm4o6W>
2. 'Improving care at the end of life: A report of the Aspen Institute Health Strategy Group,' 2016. [Noted in the 22 May 2017 issue of Media Watch (#513, p.16)] **Download/view at** <https://goo.gl/XVPJRU>

International

Invisible people: Why Ukraine needs to take palliative care seriously

UKRAINE | Open Democracy – 3 May 2018 – Ukraine's constitution is full of references to a decent life, but there's no mention of a decent process of dying or death. For public officials, deaths are a mere statistic. For medics they are data which needs to be accounted for. But patients who receive palliative care (PC) at the end of their lives are left alone with their illnesses. If there is no prospect of recovery, they are sent home from hospital – and their families are expected to take care of the final part of their lives. In 1987, the World Health Organisation (WHO) recognised PC as a separate branch of medicine, and in 1998 added this kind care for children to the definition. According to WHO's recommendations, "palliative care" is to be introduced as soon as any life-threatening diagnosis is made. In most cases, this is a question of adults with cardiovascular problems and children with neurological conditions. The philosophy behind the definition implies a certain quality of life, and the idea that if you can't cure a patient, you can at least provide them with some help. Patients in this category should have access to a multidisciplinary medical team and a telephone

hotline. There should also be hospices for those who can't or don't want to be at home and respite care to relieve the burden on families. Ukraine confirmed a blueprint for PC in 2013, but neither national standards for this care, nor best practice guidelines, nor local treatment guidelines have yet been drawn up. For Ukrainian patients, if the term "palliative" is used, it is mainly in the context of terminal incurable cancer. <https://goo.gl/GHYDG5>

Specialist Publications

'Solidarity and compassion: Prisoners as hospice volunteers in Poland' (p.8), *Annals of Palliative Medicine*.

'Investigación sobre cuidados paliativos en México. Revisión sistemática exploratoria' (p.10), in *Cuidados Paliativos en México*.

'Cultural health literacy: The experiences of Māori in palliative care' (p.12), in *Global Health Promotion*.

Noted in Media Watch 31 October 2016 (#485, p.3):

- UKRAINE | Ukrinform (Kyiv) – 29 October 2016 – '**Children's Ombudsman: No system of palliative care in Ukraine.**' Ukrainian Children's Ombudsman Mykola Kuleba states that Ukraine has no palliative care (PC) system. "Thousands of children and their parents suffer from unbearable torments every day because of this," Kuleba said. There are more than 17,000 children in need of PC annually in Ukraine compared to UNICEF estimates of more than 40,000 such children. <https://goo.gl/2okrxR>

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Noted in Media Watch 13 August 2012 (#266, p.9):

- *PROGRESS IN PALLIATIVE CARE* | Online – 9 August 2012 – ‘**Palliative care developments in Ukraine.**’ Desk review and personal communications with palliative care (PC) providers, policy makers, patients, and volunteers suggest that Ukraine is undergoing the initial stages of PC development; limited numbers of hospices and PC units are available. Most health providers working in these facilities have only limited specialized training in PC or pain management. **Abstract:** <https://goo.gl/Rr4DyL>

Advance care directives and medical treatment decision makers: Four things for health practitioners and facilities to be aware of

AUSTRALIA (Victoria) | Lexology – Online 2 May 2018 – The new Medical Treatment Planning & Decisions Act 2016 has now been operable for almost two months. The new Act introduced legal advance care directives and changed the mechanism for appointing a person to make decisions on your behalf if you lose capacity. The Act introduced strict formal requirements for making advance care directives and appointing medical treatment decision-makers, which individuals and health practitioners must comply with. This article is intended to provide a brief overview of some of the key matters health practitioners and others working in the area have indicated they are still coming to terms with. <https://goo.gl/86PJ7k>

Four months free of chemo or six months with it?

IRELAND | *The Irish Times* (Dublin) – 30 April 2018 – You are a cancer patient, faced with the following choice: four months free of chemotherapy at the end of life or six months laden with chemotherapy at the end of your life. Which would you opt for? Put like this it's a difficult choice. But for all its delicacy, it's an important discussion to have with yourself, your family and the doctor treating you. The decision isn't about ending medical treatment, but about opting for different kinds of treatment. It is recognising that symptom control, comfort and dignity may be more important than seeking a cure. The dilemma is the focus of a recent research paper.¹ Noticing a recent trend in the regulatory approval of cancer treatments where the average survival for those treated was about six 6 months, the authors decided to look at regulatory approvals

made by the US Food & Drug Administration in the previous five years. They also looked at the ethical considerations of starting a treatment that could undermine a peaceful transition from life to death. While many oncologists will not recommend active cancer treatment when they recognise that their patients are approaching the end of life, deciding to stop chemotherapy poses a greater challenge. <https://goo.gl/YtFZ3b>

Specialist Publications

‘Palliative radiation improves life for terminal lung cancer patients – but how much is too much?’ (p.16), in *Radiology Business*.

1. ‘Cancer treatment in the last 6 months of life: When inaction can outperform action,’ *ecancermedical-science*, an online journal of the European Institute of Oncology, published online 18 April 2018. **Full text:** <https://goo.gl/XbJUMF>

Noted in Media Watch 19 February 2018 (#551, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – Accessed 17 February 2018 – ‘**End-of-life chemotherapy: A prisoner’s dilemma?**’ Despite much attention focused on end-of-life chemotherapy, many patients continue to receive chemotherapy late into their illness, providing minimal benefit and potentially causing harm. The authors describe the prisoner’s dilemma, in the context of palliative oncology, as a framework to partially explain this finding. They believe that this novel perspective will provide valuable and interesting insights to practising clinicians. Almost 10% of patients receive chemotherapy within two weeks of dying of cancer, and 60% receive treatment within two months of death. **Introductory paragraphs:** <https://goo.gl/HUUD2A>

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Noted in Media Watch 18 September 2017 (#530, p.12):

- **EXPERT REVIEW OF QUALITY OF LIFE IN CANCER CARE** | Online – 11 September 2017 – ‘**Gaps in patients’ understanding of palliative chemotherapy. Can we better communicate that treatment is not curative?**’ Misunderstanding in cancer patients receiving chemotherapy is common; 50% of cancer chemotherapy is given with palliative intent. Many patients receiving chemotherapy for incurable cancer may not understand that chemotherapy is unlikely to be curative. Cancer patients expect to share treatment decisions with their oncologist. Provision of a question prompt list and endorsement by physicians enhances patient participation in consultations and promotes patient questions about prognosis. **Abstract:** <https://goo.gl/9bsjhl>

How to look after someone with a terminal illness

U.K. (England) | *The Conversation* – 30 April 2018 – Family carers do not by and large volunteer, nor are they trained. They just find themselves with someone who needs care and they step up to the mark. Few get the support needed – at the time, or afterwards. Researchers at the Wolfson Palliative Care Research Centre included questions in the Household Survey for England about caring at the end of life.¹ The findings show that one in four people had had someone close to them die in the previous five years. Of these, one in three had provided personal care. It’s clear though from this study, that caring for someone close to you can take its toll – one in ten carers said they would not provide such care again under the same circumstances. These people were more likely to be older, and where the person had died did not have access to palliative care (PC) services. Patients without such support are also more likely to die in hospital and less likely to die at home.² Research has shown that carers are more likely to be willing to provide care again if they are supported by PC services.³ <https://goo.gl/Zsts8x>

1. ‘Family caregivers who would be unwilling to provide care at the end of life again: Findings from the Health Survey for England Population Survey,’ *Plos One*, published online 25 January 2016. [Noted in the 1 February 2016 issue of Media Watch (#447, p.15)] **Full text:** <http://goo.gl/SX1ggS>
2. ‘The complex relationship between household income of family caregivers, access to palliative care services and place of death: A national household population survey,’ published online 7 June 2017. [Noted in the 12 June 2017 issue of Media Watch (#516, p.12)] **Full text:** <https://goo.gl/Wc9w1r>
3. ‘Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study,’ *BMJ Open*, published online 31 January 2018. [Noted in the 5 February 2018 issue of Media Watch (#549, p.6)] **Full text:** <https://goo.gl/Ha3vQU>

British HIV Association Standards of care for people living with HIV

U.K. (England, Northern Ireland, Scotland & Wales) | British HIV Association – Accessed 30 April 2018 – The Standards are designed to provide a reference point against which to benchmark the quality of HIV care in the context of the changing needs of patients and the current financial pressures. They provide information to support top quality care and to inform commissioning decisions to meet the growing need for more efficient and cost-effective services. The Standards are evidence based, and have been developed in partnership with care providers, professional associations, commissioners and people living with HIV. They cover the range of care needed from testing and diagnosis to the end of life, taking a holistic view of an integrated

approach embracing overall health and well-being, as well as clinical care. **View/download at:** <https://goo.gl/L2FPSX>

Extract: Palliative care (pp.58-61)

Palliative care (PC) is a core component of any health service, ensuring that we optimise quality of life and relieve distress in the face of serious, advanced illness. There is never “nothing we can do” – PC ensures that the individual and their family are supported, receive appropriate care that meets their needs and preferences, and do not experience unnecessary suffering.

N.B. Additional articles on palliative care for people living with HIV noted in the 28 November 2016 issue of Media Watch (#489, p.10-11).

Those who accuse doctors of murdering Alfie Evans are guilty of ignorance and cruelty, says former top brain surgeon

U.K. (England) | *The Daily Mail* (London) – 28 April 2018 – Alfie Evans' parents, who fought so hard for their son, should be allowed to grieve in peace. Nobody can blame them for refusing to accept the inevitability of his death. But their grief and despair have been hijacked by mob sentiment, provoked by extremists acting as provocateurs to stir up hatred against the very people who had done so much to help him. Those who have distastefully sought to make political capital from this tragic episode include pro-life campaigners, libertarians who think the State has no place in deciding when treatment should be with-drawn, advocates of quack medicines, and even the rabble-rousing former American congressman Joe Walsh... Those who rail against the supposed injustice of Alfie's treatment would do well to read the lengthy judgment of Mr. Justice Hayden, who presided over

the High Court application for the hospital to be allowed to take Alfie off a life-support machine, a decision that ultimately brought his short life to a close. The 23-page document describes in painstaking detail how the hospital and its doctors bent over backwards to accommodate the wishes of Alfie's parents.¹ <https://goo.gl/uRbP9f>

Specialist Publications

'Alfie Evans case: Proposed law aims to prevent conflicts between parents and doctors' (p.14), in *British Medical Journal*.

'Death of Alfie Evans leaves end-of-life questions unresolved' (p.14), in *Medscape*.

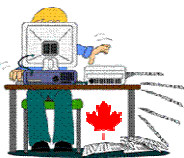
1. 'Alder Hey Children's National Health Service Foundation Trust v Evans...', Royal Courts of Justice, 20 February 2018. <https://goo.gl/DjCQuC>

N.B. Alfie Evans, a 23-month-old boy with a rare degenerative brain disease, who was at the centre of a protracted legal battle, died at Alder Hey children's hospital in Liverpool in the early hours of 28 April 2018. A representative sample of news media coverage of the Evans' case noted in the 30 April 2018 issue of *Media Watch* (#561, p.4).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- FINLAND | Sputnik International – 5 May 2018 – 'Finland slashes citizens' "dying with dignity" initiative for euthanasia.' Despite having gathered over 60,000 signatures in a matter of only several weeks, a citizens' initiative on "active death help" or euthanasia has been overwhelmingly rejected by the Finnish parliament. Nevertheless, the initiative has contributed to a passionate discussion about the end of life. The Finnish parliament has decided to reject the popular project to legalize euthanasia by a 128 to 60 vote against the initiative. Instead, a comprehensive investigation into palliative end-of-life care will be carried out... Although a clear majority of the legislators spoke against the initiative, the complexity of the issue became apparent during plenary debates, when a consensus among the parliamentary parties was reached to set up a working group to investigate the need to change the legislation on care during the final stages of life. <https://goo.gl/SMHVyK>



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>

Specialist Publications

Compassionate communities in Canada: It is everyone's responsibility

ANNALS OF PALLIATIVE MEDICINE | Online – Accessed 5 May 2018 – Professor Allan Kellehear first developed a contemporary public health approach to palliative and end-of-life care. Countries around the world have since adopted the theory of practice that mobilizes palliative care (PC) as a public health issue – particularly the Compassionate Communities (CC) model. In the wake of Canada's Medical Assistance in Dying (MAiD) legislation and its growing senior population, quality PC has enjoyed a renewed focus. Pallium Canada is helping communities across the country understand and adopt the CC model, through education, knowledge mobilization, project facilitation, and leadership. Although it has made significant strides in the last few years, there is still progress to be made. This article presents the historical development of the public health approach to end-of-life care in Canada, including its successes and hardships thus far. Drawing from examples of regional, provincial, and national initiatives, future directions for community engagement as a public health approach to PC are discussed. **Full text:** <https://goo.gl/iqE8mh>

N.B. Additional articles on “compassionate communities” and a public health perspective on end-of-life care noted in the 30 April 2018 issue of Media Watch (#561, pp.7-8).

Developing palliative care programs in Indigenous communities using participatory action research: A Canadian application of the public health approach to palliative care

ANNALS OF PALLIATIVE MEDICINE | Online – Accessed 5 May 2018 – This research contributes to the international literature on public health and palliative care (PC) in Indigenous communities. It also provides Canadian evidence of the benefits of community capacity development to create culturally appropriate PC programs. The research adds understanding of how Indigenous communities can mobilize to provide PC and illustrates the appropriateness of using the public health approach where end of life is viewed from a social, cultural and community lens. It also furthers our understanding of the keys to success for community capacity development. Four First Nations communities developed PC programs that integrated their social and spiritual practices, local health services and specialized PC expertise. This approach, fully grounded in local culture and context, can be adapted to Indigenous communities elsewhere in Canada and internationally. A workbook of culturally appropriate resources was developed that provides resources for PC program development, direct care, PC education, and engaging external partners. Policy recommendations and a policy framework to guide PC program development in Indigenous communities were created. **Full text:** <https://goo.gl/ZsemD5>

N.B. Additional articles on palliative care and end-of-life care for the Indigenous peoples of Canada noted in the 19 February 2018 issue of Media Watch (#551, p.2).

Solidarity and compassion: Prisoners as hospice volunteers in Poland

ANNALS OF PALLIATIVE MEDICINE | Online – Accessed 5 May 2018 – Over many years the project of hospice volunteering of prisoners in Poland has helped to break down stereotyping and the perceptions of prisoners, starting with the Gdansk experience, where they gradually became full members of a care team... Over 600 prisoners have passed through the hospice in Gdansk in over 10 years of cooperation. Convicts, who are mostly doing time on charges of burglary, non-payment of alimony and petty crime, see working in the hospice as a chance to change their attitudes. They see a different world, in which compassion and understanding for other people are most important. Some volunteer prisoners, after their release from a correctional facility, have been employed by the hospice in Gdansk. It is believed that such places as a hospice, where we undergo extreme experiences, can provide more radical answers to questions regarding our own attitudes. The initial data has showed that those who work in hospices receive better results in re-education and have the chance to receive a reduction of their sentence. Thanks to the correctional programs prisoners are currently working in over 40 hospices and more than 70 nursing homes, helping patients in the need of everyday care. **Full text:** <https://goo.gl/khZpqN>



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Benchmarking time to initiation of end-of-life homecare nursing: A population-based cancer cohort study in regions across Canada

BMC PALLIATIVE CARE | Online – 4 May 2018 – Several studies have demonstrated the benefits of early initiation of end-of-life (EoL) care, particularly homecare nursing services. However, there is little research on variations in the timing of when EoL homecare nursing is initiated, and no established benchmarks. This study was of patients with a cancer-confirmed cause of death between 2004 and 2009, from three Canadian provinces (British Columbia, Nova Scotia, and Ontario). Of the 28 regions, large variations in the outcome were observed, with the longest mean time (97 days) being two-fold longer than the shortest (55 days). On average, British Columbia and Nova Scotia had the first and second shortest mean times, respectively. The province of Ontario consistently had longer mean times. The empiric benchmark mean based on best-performing regions was 57 mean days. **Full text:** <https://goo.gl/thc6yf>

End-of-life care in Norway

Comparing unplanned and potentially planned home deaths: A population-based cross-sectional study

BMC PALLIATIVE CARE | Online – 2 May 2018 – There is little research on number of planned home deaths. There is a need for information about factors associated with home deaths, but also differences between planned and unplanned home deaths, to improve end-of-life-care at home and make home deaths a feasible alternative. A cross-sectional study of all decedents in Norway in 2012 and 2013, using data from the Norwegian Cause of Death Registry and National registry for statistics on municipal health and care services. Among 80,908 deaths, 12,156 (15.0%) were home deaths. A home death was most frequent in circulatory diseases and cancer, and associated with male sex, younger age, receiving domiciliary care and living alone. Only 2.3% of home deaths were from dementia. In total, 41.9% of home deaths and 6.3% of all deaths were potentially planned home deaths. Potentially planned home deaths were associated with higher age, but declined in ages above 80 years for people who had municipal care. Living together with someone was associated with more potentially planned home deaths for people with municipal care. The authors' estimations indicate that even fewer people than anticipated have a potentially planned home death. **Full text:** <https://goo.gl/TTA7xk>

End-of-life in Scotland

Computer screening for palliative care needs in primary care: A mixed-methods study

BRITISH JOURNAL OF GENERAL PRACTICE, 2018;68(670):e360-e369. Though the majority of people could benefit from palliative care (PC) before they die, most do not receive this approach, especially those with multi-morbidity and frailty. GPs find it difficult to identify such patients. The aim of this study [of eight GP practices in Scotland, conducted 2016-2017] was to refine and evaluate the utility of a computer application (AnticiPal) to help primary care teams screen their registered patients for people who could benefit from PC. A search identified 0.8% of 62,708 registered patients. GPs thought the search identified many unrecognised patients with advanced multi-morbidity and frailty, but were concerned about workload implications of assessment and care planning. Patients and carers endorsed the value of proactive identification of people with advanced illness. The challenges of starting a conversation about the future remain. However, most patients regard key components of PC (proactive planning, including sharing information with urgent care services) as important. Screening for people with deteriorating health at risk from unplanned care is a current focus for quality improvement and should not be limited by labelling it solely as PC. **Full text:** <https://goo.gl/rpwx49>

Investigación sobre cuidados paliativos en México. Revisión sistemática exploratoria

(Research on palliative care in Mexico. Scoping review)

CUIDADOS PALIATIVOS EN MÉXICO, 2018;19(2):74-85. La institucionalización de los Cuidados Paliativos y el desarrollo del trabajo académico y de investigación en nuestro país ha sido paralelo con el proceso normativo iniciado con las reformas a la Ley General de Salud en 2009. Con el objetivo de describir la actividad científica desarrollada en el área de Cuidados Paliativos en México en los últimos 25 años, se realizó una revisión sistemática exploratoria para describir las características de los trabajos de investigación publicados en revistas científicas. Se calcularon las estadísticas descriptivas y se analizó el contenido. Encontramos 608 artículos, seleccionamos 81. El primer artículo data de 1992, el año con más publicaciones fue 2013 con 19. La revista nacional que más abordó el tema fue Gaceta Médica Oncológica, a nivel internacional fue Psicooncología. Las temáticas más recurrentes son: actitudes / decisiones de los profesionales, cuidados prestados al final de la vida y actividades de los equipos de cuidados paliativos. La enfermedad más estudiada es el cáncer. Quienes mantienen el liderazgo en las publicaciones son médicos con una mirada clínica y epidemiológica, en revistas de bajo impacto y distribución nacional. **Full text:** <https://goo.gl/w2EJmV>

N.B. In recent years there has been little in the English language literature on palliative care in Mexico, particularly in the context of ongoing research on end-of-life care, hence inclusion in Media Watch of this article which may be of particular interest to Spanish-speaking recipients of the weekly report. **BRA**

Pediatric palliative care and the pediatric intensive care unit

CURRENT PEDIATRICS REPORTS | Online – 28 April 2018 – The role of palliative care (PC) in pediatric critical care medicine is described, with a focus on communication practices, complex chronic medical disease, end-of-life care, and moral resiliency. PC medicine has an increasing presence in pediatric critical care medicine. The model for delivering quality PC from a primary to consultative role is evolving, as increasing numbers of patients and families benefit from this additional layer of care and advocacy. PC medicine is complementary care at all levels and focuses on collaborating with families and patients by understanding values, contextualizing the traumatic nature of their experiences, and communication through shared decision-making. Enhancing and strengthening PC skills of pediatric intensive care unit clinicians will provide one possible mechanism for addressing moral distress. PC is an essential component of comprehensive care for our patients and families facing critical and life-threatening illness of any severity

or prognosis. It augments and complements intensive care treatments, and it is based on need, not prognosis or outcome. **Abstract (inc. list of references):** <https://goo.gl/TGKdG3>

Integrative therapies to support pediatric palliative care: The current evidence

CURRENT PEDIATRICS REPORTS | Online – 28 April 2018 – Integrative medicine offers a patient-centered approach to care that brings together conventional and complementary therapies. Evidence-based integrative therapies exist for many troublesome end-of-life symptoms, including pain, anxiety, nausea, and constipation, and offer the benefits of being low risk and non-invasive. The body of evidence on integrative therapies for pediatric palliative care is still small, but interest and use among patients and providers are stimulating increased research efforts, which are summarized here. **Abstract (inc. list of references):** <https://goo.gl/C2agyE>

Noted in Media Watch 22 January 2018 (#547, p.17):

- *PEDIATRIC CRITICAL CARE MEDICINE* | Online – 11 January 2018 – ‘**The importance of parental connectedness and relationships with healthcare professionals in end-of-life care in the pediatric intensive care unit.**’ This study explores what interaction with hospital staff is meaningful to parents in existential distress when their child is dying in the pediatric intensive care unit (PICU). Parents’ narratives of their child’s end-of-life stage in the PICU bespeak experiences of estrangement, emotional distancing, and loneliness. **Abstract:** <https://goo.gl/4krMXv>

Cont.

N.B. Additional articles on end-of-life and bereavement care in pediatric intensive care units noted in the 2 October and 28 August 2017 issues of Media Watch (#532, p.6 and #527, p.13, respectively).

Related

- *PEDIATRICS* | Online – 2 May 2018 – ‘**Benefits of early referral to pediatric palliative care for a child with a rare disease.**’ This case is described to provide a voice for families who are caring for a child with an undiagnosed or life-limiting illness, and especially for the families who won’t consider pediatric palliative care (PPC) either out of fear or not knowing it exists. Policy and funding frameworks need to support the reality of PPC and our home care system needs to be flexible to the fluctuating needs of children or the reality will be that services are not there when required, and we could miss supporting a family at home when that had been their wish all along. **Full text:** <https://goo.gl/wSMDYz>

Impact of natural disasters on children receiving palliative care lessons learned from Hurricane Harvey

CURRENT PEDIATRICS REPORTS | Online – 27 April 2018 – The authors discuss the implications of natural disasters for pediatric palliative care (PC) patients and suggest a series of best practices for patients, their families, and their healthcare providers. Data from the aftermath of Hurricane Katrina [in August 2005] provide insight into the effects of natural disasters on children with chronic medical conditions. The authors supplement this with details from their recent experience caring for pediatric PC patients during Hurricane Harvey [in August-September 2017] as well as new data about grief and bereavement in the context of natural disasters. Pediatric PC patients are a group that should be considered at high risk in the setting of a natural disaster. They are at increased risk of new medical problems or exacerbations of chronic conditions. Additionally, their past history places them at increased risk for disturbances in their psychosocial functioning including posttraumatic stress syndrome. This highlights the need for increased involvement of pediatric PC teams in preparation for a natural disaster, during the event, and in the aftermath. **Abstract (inc. list of references):** <https://goo.gl/Wec8e5>

Noted in Media Watch 30 April 2018 (#561, p.11):

- *JOURNAL OF INTERNATIONAL HUMANITARIAN ACTION* | Online – 20 April 2018 – ‘**Palliative care in humanitarian crises: A review of the literature.**’ Analysis of 95 peer-reviewed and gray literature documents reveal a scarcity of data on palliative care (PC) needs and interventions provided in crises, challenges of care provision particularly due to inadequate pain relief resources and guidelines, a lack of consensus on the ethics of providing or limiting PC as part of humanitarian healthcare response, and the importance of contextually appropriate care. **Full text:** <https://goo.gl/N8cZxA>

N.B. Additional articles on the provision of palliative care during humanitarian crises or natural disasters noted in this issue of Media Watch.

Field perspective palliative care: Taking the long view

FRONTIERS IN PHARMACOLOGY | Online – 26 April 2018 – Our medicalised modern cultures render reason and mystery mutually exclusive, define death by disease as failure, and dying as disgraceful. Providers and policymakers alike marginalise ageing and dying individuals, formulating largely ineffective strategies without palliative care (PC) and pain relief budgets. PC acknowledges that each life is morally significant, restoring patients’ and families’ quality of life where possible, and attending meticulously to the dying period as necessary. Hospices are far more than mere buildings; they house an ethos of care. The field is currently challenged by its variable situation over the world and the pressing need to incorporate new technology to its practice. This article provides a review of some important milestones in the history and development of PC and evolution of palliative medicine in some countries, some current issues concerning consistency in its implementation, and some likely prospects for its future advance and expected expansion, from the perspective of one central question: “What constitutes the ethos of PC replicating its foundational philosophy and principles?” which helps to set the scene for possible future advances to integrate ethical, legal and social implications. **Abstract:** <https://goo.gl/qUVD4D>

Cultural health literacy: The experiences of Māori in palliative care

GLOBAL HEALTH PROMOTION | Online – 3 May 2018 – This study found that there were several factors that impacted on the study's participants' ability to access, understand and utilise information in a palliative care (PC) setting. The first factor was the willingness and ability of health professionals to have clear and timely conversations with patients and whānau (families) about the move from active treatment to PC. Until those "hard conversations" were held, whānau had no way of understanding care options or predicting the trajectory of the illness. The second factor relates to the cultural health literacy of the organisation. This was important for being able to transmit information in acceptable and understandable ways. More than sharing information, however, was the question of whether the inherent context of hospices and other PC services were compatible with the Māori worldview. For some of our participants the differences in the aims of such care were insurmountable, and they either chose not to receive care or delayed accessing services until the last possible moment. Patients and whānau in this study developed complex health literacy practices to work around the cultural and communication barriers demonstrated by the PC environment. Cultural health literacy is an area which requires urgent attention if PC is to be provided equitably in Aotearoa (i.e., New Zealand). **Full text:** <https://goo.gl/SWnXQJ>

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

Addressing palliative and end-of-life care needs with Native American elders

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2018;24(4):160-168. Life-limiting illness plagues Native Americans, yet access to palliative and end-of-life care, including hospice care, is severely limited. This study aimed to explore palliative and hospice care with Native American elders and tribal health educators on a Northern Plains reservation in the U.S. Opportunities were present for improving cultural awareness and advance directive education to elders. Challenges raised were related to infrastructure, tribal government and the Indian Health Service. Needs identified included cultural awareness and language education for health-care providers and advance directive education. **Abstract:** <https://goo.gl/SsL3AA>

Noted in Media Watch 31 July 2017 (#523, p.11):

- *JOURNAL OF TRANSCULTURAL NURSING* | Online – 22 July 2017 – '**Culturally relevant palliative and end-of-life care for U.S. indigenous populations: An integrative review.**' Twenty-nine articles were identified. Seventeen described culturally specific palliative and end-of-life care (P&EoLC), and revealed four themes: 1) Communication; 2) Cultural awareness/sensitivity; 3) Community guidance for P&EoLC programs; 4) Barriers ...and, two subthemes: 1) Trust/respect; and, (2) Mistrust. Limitations are lack of research funding, geographic isolation, and stringent government requirements. **Abstract (inc. list of references):** <https://goo.gl/yegFi2>

N.B. Additional articles on palliative and end-of-life care for U.S. indigenous populations noted in this issue of Media Watch.

Association between hospice length of stay, health care utilization, and Medicare costs at the end of life among patients who received maintenance hemodialysis

JAMA INTERNAL MEDICINE | Online – 30 April 2018 – Patients with end-stage renal disease are less likely to use hospice services than other patients with advanced chronic illness. The authors examined the association between hospice length of stay and health care utilization and costs at the end of life among Medicare beneficiaries who had received maintenance hemodialysis. Overall, 41.5% of hospice enrollees who had been treated with hemodialysis for their end-stage renal disease entered hospice within three days of death. Although less likely to die in the hospital, and to receive an intensive procedure, these patients were more likely than those not enrolled in hospice to be hospitalized and admitted to the ICU, and they had similar Medicare costs. Without addressing barriers to more timely referral, greater use of hospice may not translate into meaningful changes. **Abstract:** <https://goo.gl/pc2kPg>

Literature review

How well do Physicians' Orders for Life-Sustaining Treatments (POLST) forms assure that patients get the end-of-life care they requested?

JOURNAL OF FAMILY PRACTICE, 2018;67(4):249-251. Quite well, for cardiopulmonary resuscitation (CPR). Most patients (91%-100%) who select "do not resuscitate" (DNR) on their physician's orders for life-sustaining treatment (POLST) forms are allowed a natural death without attempted CPR across a variety of settings (community, skilled nursing facilities, emergency medical services, and hospice). Few patients (6%) who select "comfort measures only" die in the hospital, whereas more (22%) who choose "limited interventions," and still more (34%) without a POLST form, die in the hospital (strength of recommendation [SOR]: B, large, consistent cross-sectional and cohort studies). Most patients (84%) who select "attempt resuscitation" receive resuscitation for out-of-hospital cardiac arrest in emergency services settings (SOR: B, small retrospective cohort study). POLST orders declining other services (intravenous fluids, intensive care, intubation, feeding tubes) are carried out in most (84%-100%) cases. POLST orders regarding antibiotic treatments are less effectively implemented (SOR: B, moderate-sized retrospective chart review). **Full text:** <https://goo.gl/CBq5PG>

Impact of a six-year project to enhance the awareness of community-based palliative care on the place of death

JOURNAL OF PALLIATIVE MEDICINE | Online – 3 May 2018 – This study examined the clinical outcomes of a six-year project to enhance the awareness of palliative care (PC), consisting of three intervention approaches: performing outreach, providing PC education for community-based medical professionals, and effectively using a newly developed information-sharing tool, Regional Referral Clinical Pathway for Home-based Palliative Care. These approaches were effective to time-dependently increase the home death rate as a clinical outcome. In previous studies, difficulty in appropriately performing procedures not covered by home care physicians, such as catheter management and expensive drug administration, tended to be a barrier to home care. Based on this, the outreach approach provided in this study may have contributed to the increase in the home death rate. Furthermore, it has been reported that once patients are hospitalized due to deterioration, the probability of discharge decreases, consequently increasing hospital deaths. Prompt consultation and management provided by PC specialists are needed to prevent such situations. The outreach approach may have contributed to this. **Full text:** <https://goo.gl/oLsgv7>

Cannabis in end-of-life care: Examining attitudes and practices of palliative care providers

JOURNAL OF PSYCHOACTIVE DRUGS | Online – 1 May 2018 – Medical cannabis research has become quite extensive, with indications ranging from glaucoma to chemotherapy-induced nausea. Despite increased interest in cannabis' potential medical uses, research barriers, cannabis legislation, stigma, and lack of dissemination of data contribute to low adoption for some medical populations. Of interest, cannabis use appears low in palliative care (PC) settings, with few guidelines available to PC providers. The authors sought to examine the attitudes, beliefs, and practices of PC providers regarding the use of cannabis for terminally ill patients. Results [of an online survey] demonstrated that PC providers endorse cannabis for a wide range of symptoms, end-of-life care generally, and as an adjuvant medication. Nevertheless, the gap between these beliefs and actual recommendation or prescription appears vast. Many who support the use of cannabis in PC do not recommend it as a treatment. These data suggest recommendations for healthcare providers and PC organizations. **Abstract:** <https://goo.gl/8AQ1Bp>

Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Prompt palliative care saves money, especially in sickest patients

MEDPAGE TODAY | Online – 30 April 2018 – Providing a palliative care (PC) consultation right after admission in patients with a complex illness will shorten their hospital stay and provide significant cost savings, particularly for patients with cancer and/or multiple comorbidities, a large, international study showed.¹ Results from a meta-analysis conducted by scientists at the Icahn School of Medicine at Mount Sinai in New York City and Ireland's Trinity College Dublin showed that adding a PC consultation to routine care within 3 days of hospital admission saved an average of U.S. \$3,237 per patient when compared with patients who did not receive PC. The economic impact of prompt PC was greatest in patients with a diagnosis of cancer compared with those with a non-cancer diagnosis... PC was associated with a cost savings per hospital stay of \$4,251 per cancer patient and \$2,105 per hospital stay for patients diagnosed with a non-cancer illness... The analysis also showed that the impact of PC on the length and cost of hospital stay was also more significant in patients with four or more comorbidities compared with those with two or fewer comorbidities, regardless of the primary diagnosis. "Our results suggest that acute care hospitals may be able to reduce costs for this population by increasing PC capacity to meet national guidelines," the team wrote. For example, in the American Society of Clinical Oncology's current guideline statement on the integration of PC into clinical practice, the expert panel recommended that patients with advanced cancer, whether treated on an inpatient or outpatient basis, "should receive dedicated PC services, early in the disease course, concurrent with active treatment." <https://goo.gl/yQ2h7q>

1. 'Economics of palliative care for hospitalized adults with serious illness: A met-analysis,' *JAMA Internal Medicine*, published online 30 April 2018. **Full text:** <https://goo.gl/YDacjn>
2. 'Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update,' *Journal of Clinical Oncology*, 2017;35(1):96-112. [Noted in the 31 October 2016 issue of *Media Watch* (#486, p.7)] **Full text:** <https://goo.gl/RGjFMP>

Death of Alfie Evans leaves end-of-life questions unresolved

MEDSCAPE | Online – 1 May 2018 – The death of Alfie Evans, the 23-month-old terminally ill British youngster, closes a chapter on a tragic case that exposed in the full glare of media attention the friction that can arise in end-of-life cases when families and healthcare professionals are at loggerheads over what is best for a child. The failure of Alfie's parents to resist medical opinion, overturn court judgements, and have the final say in their son's care led to a backlash from the family's supporters, who mounted an online campaign and demonstrated against administrators and medical staff at Alder Hey Children's Hospital in Liverpool, England, where Alfie had been treated. This led to heightened security and a police presence at the hospital amid complaints from hospital authorities that staff had been subjected to "highly abusive and threatening language and behaviour." However, experts in medical law say the decision of the courts to back health professionals in this case should not come as a surprise. "The only test is what is in the best interests of the child," said Charles Foster, a practising barrister ... specialising in medical law and a fellow of Green Templeton College at the University of Oxford.

"The second thing to understand is that the child is a distinct legal and ethical entity from its parents, and of course you don't normally take other people's interests into account in deciding on the best interests of a completely distinct person." The case of Liverpool-born Alfie Evans centred on his parents' belief that they were entitled to the final word on his treatment, irrespective of the professional assessments, which said there was nothing the medical profession could do for their son. **Full text:** <https://goo.gl/2i4KpX>

Alfie Evans case: Proposed law aims to prevent conflicts between parents and doctors

BRITISH MEDICAL JOURNAL | Online – 30 April 2018 – Doctors, lawyers, ethicists, politicians, and parents are working on proposals to improve the way disputes between parents and doctors over children's treatment are handled, after a series of bitter court battles have shown up problems with the current system. The move was announced the day before Alfie Evans ... four and a half days after he was removed from the ventilator that was keeping him alive. **Introduction:** <https://goo.gl/5ZhNCP>

Cont.

N.B. A representative sample of news media coverage of the Evans' case noted in the 30 April 2018 issue of Media Watch (#561, p.4). Similar, high profile cases: Charlie Gard, Jahi McMath, Baby K and Baby Joseph, noted in the 1 January and 16 & 23 April 2018 issues of Media Watch (#544, p.25, #559, p.9, and #560, p.9, respectively).

Related

- *JOURNAL OF MEDICAL ETHICS* | Online – 3 May 2018 – ‘**Charlie Gard: In defence of the law.**’ The first part of this article sets out the basic legal framework that operates when parents seek potentially life-sustaining treatment that doctors believe is against a child’s best interests and describes the criticisms of that framework. The second part suggests an alternative approach that would give decision-making power to parents, and remove doctors’ ability to unilaterally withhold or withdraw life-sustaining treatment that they regard as futile. This proposal is grounded in several values the authors argue should guide these regulatory choices. They contend that the best interests test is justifiable and since the courts show no sign of departing from it, the focus should be on how to better elucidate the underlying values driving decisions. The authors defend the current role that the judiciary plays as an independent state-sanctioned process with a precedent-setting function. **Abstract:** <https://goo.gl/FTEH3E>

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

Religious preference and hospice choice

OMEGA – JOURNAL OF DEATH & DYING | Online – 3 May 2018 – The authors employed a database from a large hospice provider with offices in 16 states to examine the impact of religious preference on hospice choice. Little work has been done on this issue, even though religion is the only social institution that specifically addresses the end of life (EoL). Hospice work, in particular, has drawn little attention despite it effecting millions of patients and their families. Of all the medical sub-specialties, hospice is one of the most effected by society’s views on death and religious views of dying. It is also the only government-funded medical service that requires religious support be made available to patients. The authors’ hypothesis is that certain religious groups have a predisposition against EoL interventions and will be less likely to utilize hospice. This impacts a multi-billion dollar a year industry that supplies hospice service to millions of patients, and this research points to one major religious group not accessing their hospice benefit at the same rate as other denominations. **Full text:** <https://goo.gl/ecqi3U>

Noted in Media Watch 23 January 2017 (#496, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 19 January 2017 – ‘**A systematic review of religious beliefs about major end-of-life issues in the five major world religions.**’ The authors’ search strategy generated 968 references, 40 of which were included for this review. Whenever possible, they organized the results into five categories that would be clinically meaningful for palliative care practices at the end-of-life (EoL): 1) Advanced directives; 2) Euthanasia and physician-assisted suicide; 3) Physical requirements (artificial nutrition, hydration, and pain management); 4) Autopsy practices; and, 5) Other EoL religious considerations. **Abstract (inc. list of references):** <https://goo.gl/0Lh72z>

End-of-life care in England

The difficulties of discharging hospice patients to care homes at the end of life: A focus group study

PALLIATIVE MEDICINE | Online – 30 April 2018 – To the authors’ knowledge, the views of hospice staff on hospice-to-care-home discharge have not been previously reported in the literature. Hospice multidisciplinary team members find these discharges challenging. Further research is required to understand patients’ and their family members’ views and experiences of transfers to care homes at the end of life (EoL). It is time for hospices to focus on relocation distress at the EoL, to foster improved relationships between their inpatient staff and local care homes, and to focus on better continuity and patient and family support during and after the transfer process, including in bereavement. There is need for recognition that people are frequently admitted to care homes explicitly for EoL care. **Full text:** <https://goo.gl/e5ow6r>

Cont.

Noted in Media Watch 1 August 2016 (#473, p.16):

- *PALLIATIVE MEDICINE* | Online – 28 July 2016 – ‘**Inpatient transfer to a care home for end-of-life care: What are the views and experiences of patients and their relatives? A systematic review and narrative synthesis of the U.K. literature.**’ Many patients were reported to have been negative or ambivalent about moving and experienced feelings of anxiety or abandonment when transferred. Relatives were often either vehemently opposed or ambivalent. Although some came to accept transfer, others reported the transfer to have seriously affected their loved one’s quality of life and that the process of finding a care home had been traumatic. No studies investigated patients’ views prospectively, the views of staff or the processes of decision-making. **Abstract (inc. list of references):** <http://goo.gl/3BsLhu>

Disparities in access to palliative medication: The duty of the state to ensure opioid medication access

PENN BIOETHICS JOURNAL, 2018;13(2):10-14. Opioid analgesics, specifically codeine and morphine, are registered on the World Health Organization’s Essential Medicines List, yet these medications are not available to patients in more than 150 countries... As a result, more than 5.5 billion people are left with little to no access to chemical palliation, including millions of terminal cancer and end-stage HIV/AIDS patients... The government of each country must engage with the International Narcotics Control Board to obtain any supply of narcotic medication for its people. However, the high administrative burden to order and track the annual distribution of opioids means the governments of most developing countries cannot attain any narcotics supply. Advocates for ample access to chemical palliation contend that governments have a duty to make opioid analgesics available to the patients who require them. The authors analyze the proposed obligation in the context of the principles of medical ethics – beneficence, non-maleficence, autonomy, and justice. A utilitarian evaluation reveals that the government indeed has a duty to its people to secure adequate access to opioid medication. As such,

countries ought to pass laws to officially recognize their responsibility to close the global disparity in access to palliative medication. **Complete issue of the journal (scroll down to p.10):** <https://goo.gl/Mm3M2m>

Opioid pain relief in different countries

U.S. gets 30 times more opioid pain relief medication than it needs

Mexico gets only 36% of what it needs

China gets about 16% of what it needs

India gets 4% of what it needs

Nigeria gets just 0.2% of what it needs

Source: The Lancet Commission on Global Access to Palliative Care & Pain Relief: <https://goo.gl/h8eBLc>

N.B. ‘Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,’ *The Lancet*, published online 12 October 2017. [Noted in the 16 October 2017 issue of Media Watch (#534, p.14)]
Full text: <https://goo.gl/i7r9M1>

Palliative radiation improves life for terminal lung cancer patients – but how much is too much?

RADIOLOGY BUSINESS | Online – 30 April 2018 – More than a third of patients diagnosed with terminal lung cancer undergo palliative radiation therapy that can improve their quality of life, but more than half of those individuals could be experiencing overtreatment.¹ Palliative radiation therapy is a standard course of treatment in patients with incurable non-small cell lung cancer, because those patients are often focused more on prolonging life comfortably and less on a cure... But the palliative approach, which typically focuses on the brain, thorax and bone, could be one that’s utilized inefficiently. One meta-analysis found higher-dose radiation therapy schedules were linked to minor improvements in symptom control and survival; those developments came at the cost of increased short-term side effects... <https://goo.gl/Wixhx4>

1. ‘Palliative radiation and fractionation in medicare patients with incurable non-small cell lung cancer,’ *Advances in Radiation Oncology*, published only 23 April 2018. **Full text:** <https://goo.gl/7dEVvW>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *ARIZONA LAW REVIEW*, 2018;60(2):509-537. **“I don’t want to die, but I am dying”: Re-examining physician-assisted suicide in a new age of substantive due process.** Now, more than ever, substantive-due-process jurisprudence is positioned to recognize physician-assisted suicide (PAS) as a fundamental right. The shift away from a rigid examination of history and tradition, with more focus toward emerging awareness, will make it easier for the Court to acknowledge PAS as a fundamental right for terminally ill, competent people. In addition, the reduced emphasis on the description of the right will also be favorable to PAS. Lastly, PAS embodies the essential concepts valued by more recent cases including dignity, personal autonomy in decision-making, privacy, and liberty. Using the undue burden test as a guide, the Court could construct a PAS framework that would allow states to perform their essential safeguard functions while also supporting the dignity, autonomy and privacy of terminally ill, competent people. **Full text:** <https://goo.gl/Ktzst9>

N.B. The focus of the current issue of the *New Mexico Law Review* is “aid in dying.” Journal contents page: <https://goo.gl/YehqB2>

- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 2 May 2018 – **‘Physician-assisted suicide: Why neutrality by organized medicine is neither neutral nor appropriate.’** It has been proposed that medical organizations adopt neutrality with respect to physician-assisted suicide (PAS), given that the practice is legal in some jurisdictions and that membership is divided. The authors review developments in end-of-life care and the role of medical organizations with respect to the legalization of PAS since the 1990s. They argue that moving from opposition to neutrality is not ethically neutral, but a substantive shift from prohibited to optional. The authors argue that medical organizations already oppose many practices that are legal in many jurisdictions, and that unanimity among membership has not been required for any other clinical or ethical policy positions. Moreover, on an issue so central to the meaning of medical professionalism, it seems important for organized medicine to take a stand. They subsequently review the arguments in favor of PAS (arguments from autonomy and mercy, and against the distinction between killing and allowing to die (K/ATD)) and the arguments against legalization (the limits of autonomy, effects on the patient-physician relationship, the meaning of healing, the validity of the K/ATD distinction, the social nature of suicide, the availability of alternatives, the propensity for incremental extension, and the meaning of control). The authors conclude that organized medicine should continue its opposition to PAS. **Abstract (inc. list of references):** <https://goo.gl/d9b42R>

Media Watch: Editorial Practice

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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.

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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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Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/ZRngsv>

[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole']

Cont.

Australia

PALLIATIVE CARE WESTERN AUSTRALIA: <https://goo.gl/fCzNTL>

[Scroll down to 'International Websites']

Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: <https://goo.gl/qw5ti8>

[Click on 'National Resources,' scroll down to 'Palliative Care Network Community']



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']

SASKATCHEWAN | Saskatchewan Medical Association: <https://goo.gl/5cftPV>

[Scroll down to 'Palliative Care Network Community']

Europe



EUROPEAN JOURNAL OF PALLIATIVE CARE: <https://goo.gl/KjrR6F>

[March/April 2018 issue (Scroll down to 'The homeless: A vulnerable population with poor access to palliative care.')]

HUNGARY | Magyar Hospice Alapítvány: <https://goo.gl/3jnH7K>

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

South America



Academia Nacional de Cuidados Paliativos (Brazil): <https://goo.gl/b5CV31>

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