

Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Effecting change in the illness experience: Scroll down to **U.S.A.** and 'Caregivers draw support by mapping their relationships' (p.3), in *Kaiser Health News*.

Canada

MP McLeod arrives in Ottawa with 30,000-name petition on end-of-life care

BRITISH COLUMBIA | *Kamloops This Week* – 21 September 2017 – Kamloops-Thompson-Cariboo MP Cathy McLeod will present to the House of Commons the largest physical petition she's ever delivered – 30,000 signatures, all on paper and filling a suitcase. The petition asks the federal government to identify end-of-life and hospice care as medically necessary service under the Canada Health Act. It was gathered by the Kamloops Catholic Women's Defence league. The paper petition largely has signatures from within the riding, although there are also a minority of names from outside Kamloops-Thompson-Cariboo. The petition must be certified by clerks of the [House of] Commons. After it is presented by McLeod in the House, the federal government is duty bound to respond. <https://goo.gl/w7ZKxv>

Noted in Media Watch 5 June 2017 (#515, p.2):

- ONTARIO | *Lambton Shield* – 31 May 2017 – 'Gladu's palliative care bill passes third reading.' Sarnia-Lambton MP Marilyn Gladu's private member's bill, which was introduced in the House of Commons in May 2016, has passed third reading with unanimous [i.e., all-party] support and is on its way to the Senate. Bill C-277 – also known as an Act providing for the development of a 'Framework on Palliative Care in Canada' – would require the Minister of Health to develop and implement a framework designed to give all Canadians access to palliative care provided through hospitals, home care, long-term care facilities, and residential hospices. <https://goo.gl/cZvLDH>

N.B. Sarnia-Lambton's Member of Parliament in the federal government was recently named Shadow Minister of Health in Opposition.

Specialist Publications

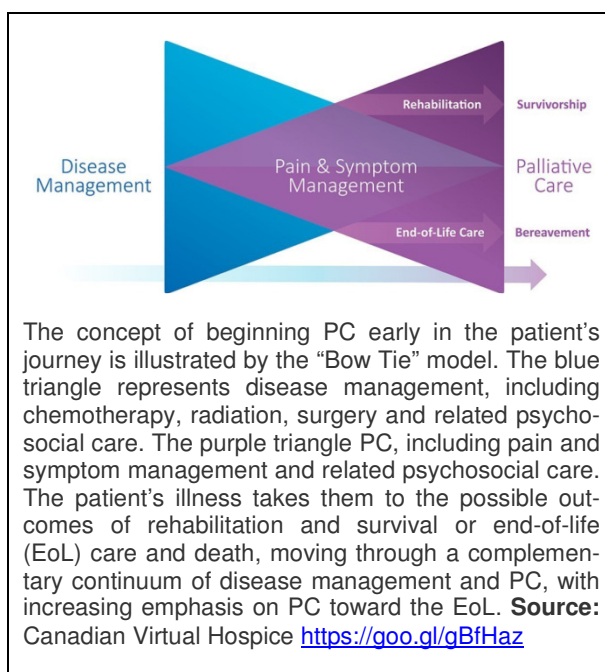
'Approach to advanced heart failure at the end of life' (p.9), in *Canadian Family Physician*.

'Law Commission of Ontario presents findings from end-of-life project' (p.15), in *The Lawyer's Daily*.

Palliative care not yet a routine part of full cancer experience: New report

CANADIAN PARTNERSHIP AGAINST CANCER | Online – 18 September 2017 – The Partnership has released a report on the state of palliative and end-of-life care (EoLC) for people with cancer in Canada.¹ The report finds patients who could benefit from palliative care (PC) are not being identified, assessed and referred early enough in their cancer experience so that appropriate care can be part of treatment as soon as possible. Evidence suggests earlier integration of PC has the potential to improve treatment outcomes and prolong survival. [See sidebar ►] Evidence also reinforces that EoLC provided at home improves quality of life for people with cancer and reduces unnecessary and repeated hospital stays. “We must redefine PC. This type of physical, psychosocial and spiritual support should not be so closely associated with EoLC, and should be incorporated soon after a cancer diagnosis,” said Dr. Deborah Dudgeon, Senior Scientific Leader, Person-Centred Perspective, at the Partnership. “The World Health Organization defines PC as ‘relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems.’ We need to start following this definition in our approach to cancer treatment.” The Partnership’s report provides data and insights from Canadians with cancer and their caregivers on experiences with PC. Data suggest people with

cancer who die in acute-care hospitals do not always receive inpatient PC early in their illness.^{2,3} Over 66% received inpatient PC only during their last hospitalization before death, which can be too late for patients to experience the full benefits of this type of physical and emotional support. <https://goo.gl/dwSQ54>



1. ‘Palliative and End-of-Life Care: A Cancer System Performance Report,’ Canadian Partnership Against Cancer, September 2017. **Download/view report at:** <https://goo.gl/1X1mfP>
2. ‘Early palliative care for patients with metastatic non-small-cell lung cancer,’ *New England Journal of Medicine*, 2010;363(8):733-742. [Noted in Media Watch 23 August 2010 (#163, p.8)] **Full text:** <https://goo.gl/SAkjsc>
3. ‘Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial,’ *The Lancet*, 2014;17;383(9930):1721-1730. [Noted in Media Watch 22 December 2014 (#389, p.15)] **Abstract:** <https://goo.gl/xckfvP>

Noted in Media Watch 21 August 2017 (#526, p.13):

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 16 August 2017 – ‘**Palliative care in special settings of cancer care.**’ Within oncology, surgical, radiation, medical, gynecologic, malignant hematologic, transplantation, and pediatric fields are distinct tribes with distinctive rites and rituals of usual behavior that are carried out in special settings. Successful integration of palliative care requires a keen and unabashed recognition of this. **Full text:** <https://goo.gl/ccMPQb>

N.B. The integration of palliative care into standard oncology care is the focus of several articles published recently in the *Journal of Oncology Practice* and noted in the 28 August 2017 issue of Media Watch (#527, pp.3,5,11-12).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- Quebec | CTV News (Montreal) – 21 September 2017 – **‘91% of caregivers want medical aid in dying law expanded to Alzheimer’s patients: Study.’** A Quebec Federation of Alzheimer’s Groups ... study revealed nine of ten caregivers surveyed said the law should be changed to cover Alzheimer’s patients in the terminal stages of the diseases if they expressed their wishes clearly beforehand in writing. Under the current law, people diagnosed with Alzheimer’s disease don’t have the right to ask for medically assisted death unless they are in the terminal phase of the disease. By the time they are in the terminal phase, however, they are often deemed to be no longer psychologically able to make the request. The current Quebec medical aid in dying law only allows those who have explicitly decided for themselves, in full possession of their mental faculties, that they want that option. <https://goo.gl/acJ9qL>
- BRITISH COLUMBIA | CTV News (Vancouver) – 18 September 2017 – **‘Plaintiff in assisted dying court challenge gets medical help to die.’** One of two British Columbia women challenging the federal government’s restrictive law on medically assisted dying has finally been able to end her suffering with the help of a doctor. But Robyn Moro’s case will continue to be part of the constitutional challenge, held up as an example of the torment individuals can be forced to endure due to uncertainty over the law’s requirement that a person’s natural death must be “reasonably foreseeable.” The 68-year-old suffered constant, excruciating pain from Parkinson’s disease but her doctor, Ellen Wiebe, determined last March that she was not eligible for assistance in dying because she was not near death. Wiebe changed her mind last month, based on an Ontario Superior Court ruling in June that sought to ease physicians’ fears that they could be prosecuted for murder if they helped a 77-year-old woman, known only as AB, end her life when her natural death was not imminent. <https://goo.gl/2AkH8C>
- NOVA SCOTIA | *The Chronicle Herald* (Halifax) – 18 September 2017 – **‘The next battleground in Canada’s euthanasia debate: Advance directives.’** Liana Brittain says each additional day with her husband would have been a precious gift, but a gap in Canada’s assisted-suicide law cut those short. Bill C-14 revolutionized end-of-life care when it was enacted last summer, but it doesn’t permit people to leave what are known as “advance directives” – written instructions for assisted suicides, for a time when they are no longer able to ask for it. While Canadians like Brittain favour allowing advance directives, as did a special parliamentary committee that studied the issue, the Liberal government put off any decision. It has appointed the Council of Canadian Academies to examine the issues, and that group has formed an expert panel to gather submissions. <https://goo.gl/F9cWdb>

U.S.A.

Caregivers draw support by mapping their relationships

CALIFORNIA | *Kaiser Health News* – 21 September 2017 – CareMaps are an intriguing new tool created by the Atlas of Caregiving, an ambitious project that hopes to gather comprehensive data about family caregivers. The project’s pilot study examined 14 families in the San Francisco Bay Area who wore miniature cameras and sensors, kept a log of their activities and participated in extensive in-person interviews. One of the goals was to understand what Rajiv Mehta, the project’s founder, calls the “ecosystem of family caregiving, the relationships that surround caregivers and that shape their experiences.” One family caregiver might be at odds with her siblings but have a close group of friends she can turn to for emotional support as she cares for a disabled husband, for example. Another might be divorced but have a son living at home who can help with practical responsibilities as he cares for his mother with Parkinson’s disease, who moved in a year ago. Yet another couple in their 60s, both struggling with serious illness, may rely primarily on their three children, all living nearby, but have few friends. How could these webs of relationships – people who are caring for each other and who are cared for, in turn, by others – be portrayed? <https://goo.gl/eu47hB>

N.B. Atlas of Caregiving: <https://goo.gl/vxid3W>

End-of-life chatbot can help you with difficult final decisions

MASSACHUSETTS | *New Scientist* – 18 September 2017 – Could chatbots lend a non-judgemental ear to people making decisions about the end of their life? People near the end of their lives sometimes don't get the chance to have these important conversations before it's too late, says Timothy Bickmore at Northeastern University in Boston, Massachusetts. So Bickmore and his team – which included doctors and hospital chaplains – built a tablet-based chatbot to offer spiritual and emotional guidance to people that need it. “We see a need for technology to intervene at an earlier point,” he says. And it has already seen some success. Bickmore's team initially tested the chatbot with 44 people aged 55 and over in Boston. Just under half those adults had some kind of chronic illness, and nearly all had spent time with someone who was dying. After spending time talking to the chatbot, most of the participants reported they felt less anxious about death and were more ready to complete their last will and testament. <https://goo.gl/fGKnhV>

Related

- NEBRASKA | *The Lincoln Journal Star* – 20 September 2017 – ‘**Nebraskans are comfortable talking about death, but don't sign important documents.**’ A strong majority of Nebraskans – 84% – are comfortable talking about death. Most also know what an advanced health care directive is and understand the importance of a health care power of attorney or a living will. Only about 30% of those people have actually completed an advanced health care document, according to a state-wide survey conducted by the University of Nebraska-Lincoln Bureau of Sociological Research. <https://goo.gl/jEa5jP>

New law limits doctors' ability to invoke DNR without patient consent

TEXAS | *The Houston Chronicle* – 18 September 2017 – Beginning next April, the right of Texas hospitals and doctors to write unilateral DNRs will be dramatically curtailed under a law signed by Governor Greg Abbott last month. The law requires doctors and hospitals to notify and get consent from patients or their guardians before implementing a DNR order. The likely impact of the law is unclear, given that most hospitals already have policies calling for doctors to get such approval before writing a DNR. More than one critic called it “a solution in search of a problem,” and bioethicist Thaddeus Pope said its value may be “more symbolic than practical.” Pope cited laws passed recently in Kansas, Oklahoma, New York and Idaho as examples of

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‘**End-of-life practice patterns at U.S. adult cystic fibrosis care centers: A national retrospective chart review**’ (p.13), in *Journal of Cystic Fibrosis*.

‘**Provider-prioritized domains of quality in pediatric home-based hospice and palliative care: A study of the Ohio Pediatric Palliative Care & End-of-Life Network**’ (p.14), in *Journal of Palliative Medicine*.

‘**Ethics and the legalization of physician-assisted suicide: An American College of Physicians position paper**’ (p.17), in *Annals of Internal Medicine*.

‘**Oregon's Death With Dignity Act: 20 years of experience to inform the debate**’ (p.18), in *Annals of Internal Medicine*.

Specialist Publications

‘**When cardiopulmonary resuscitation becomes harmful**’ (p.16), in *National Catholic Bioethics Quarterly*.

Cont.

Noted in Media Watch 16 January 2017 (#495, p.6):

- *THE HASTINGS REPORT* | Online – 11 January 2017 – ‘**After the DNR: Surrogates who persist in requesting cardiopulmonary resuscitation.**’ Some health care organizations allow physicians to withhold cardiopulmonary resuscitation (CPR) from a patient, despite patient or surrogate requests that it be provided, when they believe it will be more harmful than beneficial. Although there is state-to-state variability in the U.S. and a considerable judicial gray area about the conditions and mechanisms for refusals to perform CPR, medical teams typically follow a set of clearly defined procedures for these decisions. **Abstract:** <https://goo.gl/4CyvmX>

N.B. For a European perspective on resuscitation see the 14 August 2017 issue of Media Watch (#525, p.9).

Related

- TEXAS | *The Huston Chronicle* – 22 September 2017 – ‘**Judge lets one-of-a-kind “futile care” law stand.**’ In a victory for Texas’ medical community, a Harris County state district judge Friday rejected a lawsuit challenging the constitutionality of a state law that allows doctors to withdraw life-sustaining treatment against the wishes of the patient or guardian. Judge Bill Burke said it would be “a case of throwing the baby out with the bath water” to repeal the controversial 1999 law, enacted in response to doctors’ push to eliminate care they believe prolongs suffering in terminal patients. The law, which is unique to Texas, has drawn criticism from some families who say it gives doctors too much power. <https://goo.gl/i8PCN3>

Who’s responsible for leftover home hospice care medications in Pennsylvania?

PENNSYLVANIA | Lancaster Online – 17 September 2017 – Home hospice workers are not permitted to get rid of a patient’s prescribed medications after the patient dies. State regulations forbid hospice personnel in those cases from disposing of the leftover drugs – even if they are the type of powerful, addictive controlled substances helping to feed the nation’s opioid crisis. “Pennsylvania follows (Drug Enforcement Administration) regulations,” says Dr. Joan Harrold. And that, she says, means that the medications belong to the person responsible for the patient’s estate. Harrold, chief medical officer for Hospice & Community Care in Lancaster, says hospice personnel must follow very strict guidelines in prescribing, delivering and storing the drugs in a home setting and will provide guidance to family members on how to properly dispose of them. Regulations require that hospice personnel notify patients and their families about proper disposal procedures, Harrold says. And, after death, “as we’re educating families about what to do next – what to do with the body, calling the funeral home, whether they want to bathe their loved one – we have the opportunity to address the issue of leftover medications. <https://goo.gl/JM5HmP>

Noted in Media Watch 29 May 2017 (#514, p.11):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(3):256-260. ‘**Hospice-appropriate universal precautions for opioid safety.**’ Universal precautions for opioid safety is one approach to managing the epidemic of prescription pain medication misuse that has been used in pain clinics, primary care practices, and in some hospices. In this project, a set of hospice-appropriate universal precautions was designed, drawing on hospice nursing strengths, and implemented in a mid-size hospice agency. **Abstract:** <https://goo.gl/7Wq1TE>



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>

International

England's Court of Protection

Court ruling not needed to withdraw care, judge says

U.K. (England) | BBC News (London) – 21 September 2017 – Legal permission will no longer be required to end care for patients in a permanent vegetative state, a judge has ruled. Until now a judge must also consent, even if medics and relatives agree to withdraw nutrition from a patient. But in what been described as a landmark decision, those cases will no longer have to come to court. The Official Solicitor, appointed by the state to act for such patients, is likely to appeal against the ruling. Doctors are able to withdraw treatment from a patient – if relatives consent – under various circumstances without needing court approval. Mr. Justice Jackson, who sits in the Court of Protection, made his ruling in a case concerning a 50-year-old woman who suffered from a degenerative illness for 14 years. Research by the BBC established last year that there were more than 100 patients in England & Wales in permanent vegetative or minimally conscious states. <https://goo.gl/4TqaPw>

End-of-life care in Australia

Residential aged care becoming “slow stream hospices”

AUSTRALIA (South Australia) | *Australian Ageing Agenda* – 20 September 2017 – There are more deaths from cancer in aged care facilities in South Australia than in hospices and at home combined... Residential aged care facilities are becoming slow stream hospices... In response, palliative care (PC) and aged care organisations are working more closely together with residents, families and staff who are facing end-of-life (EoL) situations more rapidly following admission to care... “It may be brutal but the first question on admission is often what funeral arrangements are in place” and “we’re now getting residents who may only be with us for 24 hours before death” were two of the observations driving a recent discussion on the issue. Aged and PC collaboration is now ongoing, instanced by the May 2017 release of ‘Respecting and meeting EoL care needs in residential aged care’ [*sic*]¹ by aged care, PC and consumer peak bodies. However, despite the closer relationship ... PC was not yet a compulsory part of [Australia-wide] Certificate III aged care training, although most students were taking it as an option in the course. <https://goo.gl/atqXrt>

Extract from *Australian Ageing Agenda* report

Across the ditch in New Zealand, hospice care has found that aligning with the Māori end-of-life beliefs and care has meant that “if we get it right for Māori we get it right for everyone,” said Mary Schumacher, chief executive of Hospice New Zealand.

N.B. Articles on Māori beliefs and practices in the context of end-of-life care are noted in the 25 April 2016 issue of Media Watch (#459, p.6)]

Specialist Publications

‘The impact of community-based palliative care on acute hospital use in the last year of life is modified by time to death, age and underlying cause of death. A population-based retrospective cohort study’ (p.16), in *Plos One*.

1. ‘Principles for Palliative & End-of-Life Care in Residential Aged Care,’ May 2017. [Noted in Media Watch 5 June 2017 (#515, p.4). <https://goo.gl/w7dmsS>



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.19.

End-of-life care in England

99% of advanced dementia sufferers not getting specialist care, finds study

U.K. (England) | *The Independent* (London) – 19 September 2017 – A survey of people in the later stages of dementia shows that a lack of palliative care (PC) services in the community means GPs and emergency services are being forced to provide most of their end of life healthcare, rather than specialist services.¹ The study ... reveals that just one per cent of advanced dementia patients had contact with specialist services such as a geriatrician or an older persons' psychiatrist. The findings, based on a survey of 85 people with advanced dementia from six clinical commissioning groups across Greater London, show that nearly one in five sufferers were seen by a paramedic in the month prior to their death, suggesting a reactive rather than planned response to patients' needs. Researchers also found that GPs were the main providers of medical care for dementia patients, with 96% of people with advanced dementia seeing a GP in their last month of life. Care homes, where the majority of people with dementia die, were found to be poorly served by secondary healthcare services, with GPs who visited homes not supported by specialist services. While PC teams may have assisted with symptom management, less than a third of participants were seen by a PC team – despite 34% being referred – and when they were, this was predominantly in the month prior to their death. <https://goo.gl/sgQCWd>

Choice in end-of-life care: Government progress

U.K. (England) | Department of Health – 21 September 2017 – 'One year on: The government response to the review of choice in end-of-life care' sets out the progress the National End-of-Life Care Programme Board has made in implementing the government's choice commitment. <https://goo.gl/Uwipt9>

1. 'Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life,' *Palliative Medicine*, published online 18 September 2017. **Full text (click on pdf icon to access):** <https://goo.gl/oC23vA>

Related

- SINGAPORE | *The Straits Times* (Singapore) – 22 September 2017 – '**Pilot palliative home-care programme improves their quality of life, lessens pain.**' When they were allowed to spend their final days at home, patients with advanced dementia ate better, showed less agitation, had less pain and needed fewer trips to the hospital, compared with those in hospices and medical facilities. Singapore's first palliative home-care programme specially for those with advanced dementia, revealed these positive results from their pilot programme ... and the people behind the effort are calling for palliative home care to be expanded as the ageing population here grows. <https://goo.gl/AC7z1y>

Noted in Media Watch 24 July 2017 (#522, p.7):

- *ANNALS OF PALLIATIVE MEDICINE*, 2017;6(4):390-392. '**Palliative care covers more than end-of-life issues: Why is this not common practice in dementia care and what are the implications?**' There is a body of literature which suggests a palliative care approach from the diagnosis onwards could help prevent unnecessary suffering and pain, enhance symptom management, enable informed decision making and help address spiritual and social aspects of care, thus contributing towards improving the quality of life of people with dementia and their families. A European Association for Palliative Care White Paper proposes a two-tier model.¹ **Full text:** <https://goo.gl/h8X26m>

1. 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,' *Palliative Medicine*, 2014;28(3):197-209. [Noted in Media Watch 8 July 2013 (#313, p.10)] **Full text:** <https://goo.gl/LoFDWE>

End-of-life care in Scotland

Taking the worry out of lung cancer

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 19 September 2017 – Lung cancer is the most common cancer in Scotland. It is also a disease with a particularly poor prognosis, with fewer than 10% of patients in Scotland surviving longer than five years from diagnosis. While there are anti-cancer treatment options, such as radiotherapy, chemotherapy or surgery, these are not appropriate for everyone due to other serious illnesses, frailty or the extent of the cancer. The agreed plan for these patients is Best Supportive Care (BSC), a palliative care approach where the priority is maintaining the best possible quality of life in the face of advancing illness. This approach has allowed many patients to receive high quality care from GPs and other professionals, but this was not the case for everyone. Patients and those close to them reported feeling uncertain about what to expect as the disease advanced and about how to access support. The opportunity for planning ahead (known

as anticipatory care planning) could be missed. A pilot project was developed by the Specialist Palliative Care team in National Health Service Fife, in partnership with the Fife Health & Social Care Partnership and Macmillan Cancer Support. Funded through the Transforming Care After Treatment programme, this innovative project defined for the first time what BSC should mean in practice for people with incurable lung cancer. <https://goo.gl/ib13F8>

Specialist Publications

'Palliative management and end-of-life care in non-malignant advanced lung disease' (p.13), in *Clinical Pulmonary Medicine*.

'A crisis in care for people with lung disease' (p.12), in *The Hippocratic Post*.

Related

- U.K. (Scotland) | *The Evening Times* (Glasgow) – 19 September 2017 – **'One in four terminally ill Scots are not getting the end of life care they need.'** One in four terminally ill people are not getting the care they need... Marie Curie, which runs a hospice in Glasgow and one in Edinburgh, as well as providing care and support services across Scotland, said a lack of specific funding for end of life care has caused a gap in services. The organisation ... said thousands of people are unable to get care they need at the end of their life. In a response to the Scottish Parliament Health & Sport Committee it said there are 56,000 people who die every year in Scotland and it is estimated that 46,000 of those will need some sort of palliative care. <https://goo.gl/MVDLrP>
- U.K. (Scotland) | *The Scotsman* (Edinburgh) – 17 September 2017 – **'Chief medical officer reveals "untold story" over invasive treatment for terminally ill.'** Dr. Catherine Calderwood told *Scotland on Sunday* how the twin pressures of a reluctance to challenge doctors and pressure from families often leads a dying patient to choose to have treatment when their own preferred option would have been to have none. Clinicians dealing with end-of-life (EoL) discussions need to involve the whole family, she said, but this discussion should never override the wishes of the terminally ill patient. Calderwood has also noted that research shows medical professionals are more likely to opt for the no-treatment route for EoL while pushing their patients down another path. <https://goo.gl/W24fiD>

N.B. Additional articles on end-of-life care in Scotland are noted in the 18 September 2017 issue of Media Watch (#530, p.7).

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | *The Australian* (Melbourne) – 20 September 2017 – ‘**Life sentence for misusing new right to die laws in Victoria.**’ The Andrews government has introduced legislation for its controversial euthanasia scheme into Victorian Parliament ... with penalties ranging up to life imprisonment for misuse. Premier Daniel Andrews today reassured voters that its pioneering voluntary assisted dying scheme was the most conservative in the world, relying on patients being able to administer the drugs themselves, and approval from two different doctors to gain access. The legislation represents Australia’s first in more than twenty years to offer terminally ill patients the right to choose when they die. Patients must be of sound mind and older than 18 years old to take part, and must be suffering an incurable illness with a prognosis of less than twelve months to live. The legislation will undergo its first reading today and second reading tomorrow, with a conscience vote to take place before the end of the year. If the Bill passes both houses of parliament, patients could access the scheme by mid-2019. <https://goo.gl/TKPQKW>

Specialist Publications

Characteristics of patients with existing advance directives: Evaluating motivations around advance care planning

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 19 September 2017 – Although 80% of patients endorse an advance directive (AD), less than 35% of American adults have a documented AD. Much research has been done on barriers to creating ADs; however, there is a paucity of research addressing motivations for creating ADs. Previous research has identified four categories of influence for engaging in advance care planning. Analysis yielded two factors representing dignity and personal control (intrinsic factors) and societal and familial influence (extrinsic factors). Intrinsic factors were the primary and most influential motivating factors among participants. Results of this study indicated that intrinsic factors were the most influential motivator among participants of all ages. They appeared to be less influential in the decision to create an AD. Motivating factors were also found to vary by age. These results may help physicians be more targeted in discussions surrounding ADs, thus saving time, which physicians identify as the main barrier in engaging in such discussions, while meeting patients’ wishes for their physicians to bring up the topic of ADs. **Abstract:** <https://goo.gl/PjSMra>

N.B. Several recently published articles offering a range of perspectives on advance care planning are noted in the 4 September 2017 issue of *Media Watch* (#528, pp.10-11).

Approach to advanced heart failure at the end of life

CANADIAN FAMILY PHYSICIAN, 2017;63(9):674-680. Unpredictable trajectories and the lack of obvious transition points in disease progression can make conversations about advance care planning with patients with advanced heart failure (HF) quite challenging. Educate patients about the uncertainty associated with HF and draw the trajectory of HF while explaining the variable nature of the illness and that each decompensation is a time when death is possible. With a better understanding of the illness and its trajectory, patients can be better prepared for end-of-life (EoL) decisions. This approach for assessment, management, and monitoring of patients with advanced HF at the EoL includes the following: set up a collaborative team, have a monitoring plan to detect exacerbations early, assess and manage symptoms, continue HF medications when possible, and have a plan to manage exacerbations. The home-based protocol for diuresis that this team has developed is used only when patients’ goals of care include being at home and focusing primarily on comfort. The protocol is initiated when patients experience a worsening of symptoms attributed to advanced HF. **Full text:** <https://goo.gl/EMDHBL>

Cont.

Noted in Media Watch 11 September 2017 (#529, p.7):

- *CURRENT HEART FAILURE REPORTS* | Online – 6 September 2017 – ‘**Cardiac palliative medicine.**’ The American Heart Association has released a policy statement recommending continuous, high-quality access to palliative care (PC) for all patients with heart failure,¹ and the Center for Medicare Services requires PC involvement in mechanical circulatory support teams. The National Quality Forum developed eight domains of PC that are required for high-quality delivery of comprehensive PC. This article assesses each domain and how it pertains to evolving care of patients with advanced heart failure. **Abstract:** <https://goo.gl/BeWC5W>

1. ‘Palliative care and cardiovascular disease and stroke: A policy statement from the American Heart Association and the American Stroke Association,’ *Circulation*, 2016;134(11):e198-e225. [Noted in Media Watch 18 September 2017 (#530, p.2)] **Abstract:** <https://goo.gl/2u9mE2>

N.B. Additional articles on end-of-life care for people living with heart failure are noted in the 28 August 2017 issue of Media Watch (#527, p.9).

Population-based models of planning for palliative care in older people

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 16 September 2017 – Health service planning requires demographic, clinical, and health systems data and is unique to each health system. Planning for palliative care (PC) in older people must include patients and their carers. This review explores literature from the last 24 months. The proportion of people living in skilled nursing facilities is increasing and many residents require quality PC. Simultaneously, the complexity of care for older people is also increasing. Systematic approaches to improving PC in these facilities have shown benefits that are cost-effective. Although advance care planning is widely promoted, a randomized controlled trial failed to show the benefits seen in non-randomized trials. This requires a reconceptualization of current programs that seek to increase uptake. Caregivers take on complex decision-making which can be stressful. By contrast, patients are often very confident that the people who are close to them will make good decisions on their behalf. Specific sub-groups considered in this review include carers (and the challenges they face), the “oldest old” and people with dementia. Excellent research is being done to improve the care of older people with palliative care needs. Ultimately, how can key findings be incorporated into clinical care? **Abstract:** <https://goo.gl/5bCLLG>

Questions on end-of-life situations twenty years after the Oviedo Contention: Stated principles and permanent uncertainties

DIRITTI UMANI E DIRITTO INTERNAZIONALE | Online – Accessed 23 September 2017 – The legal questions concerning the end of life are difficult and highly thorny. The paper seeks to offer a synthesis of the legal framework developed under the auspices of the Council of Europe, 20 years after the adoption of the Oviedo Convention.¹ The dignity of the human being is the heart of this treaty, above all when ill and dying persons are concerned. The juridical principle through which such a dignity is mainly safeguarded is that of informed consent (art. 5-9 of the Oviedo Convention). This principle, albeit clear in its general formulation, nonetheless leaves open a number of issues as far as the limits, time and form of the consent are concerned. After the analysis of the Convention, of the acts of the organs of the Council of Europe and of the case law of the Court of Strasbourg, the paper identifies some well established principles and, instead, those areas (artificial nutrition, euthanasia) still ill-defined, where a large consensus among European countries does not exist. In the final part of the paper, the author examines the project of law under discussion in Italy on the end of life questions in order to assess the compatibility of the norms to be approved by the Italian Parliament with the European legal framework as shaped in the paper. **Abstract:** <https://goo.gl/u7PWio>

1. ‘The Oviedo Convention: Protecting human rights in the biomedical field,’ Council of Europe, 1997. <https://goo.gl/w3XJ7J>

N.B. Italian language article.

End-of-life care in South Korea

Effect of the duration of hospice and palliative care on the quality of dying and death in patients with terminal cancer: A nationwide multicentre study

EUROPEAN JOURNAL OF CANCER CARE | Online – 15 September 2017 – Early referral to hospice and palliative care (HPC) has significant benefits, but little is known about the appropriate time for referral. Participants were the bereaved relatives, who were the adult primary caregivers of the 1,829 terminal cancer patients who died 2-6 months previously in nationwide centres that provide HPC in Korea. A post-bereavement survey ... of family caregivers was used to assess patients' quality of dying and death. Relative to patients who were in HPC for 3-7 days and HPC for 8-21 days, those in HPC for 22-84 days had significantly higher quality of dying. **Abstract:** <https://goo.gl/Gw12P7>

Noted in Media Watch 20 June 2016, #467 (p.13):

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2016;19(2):99-108. '**Hospice palliative care in South Korea: Past, present, and future.**' Hospice and palliative care in Korea has developed steadily since its introduction in 1965. Currently, it is targeted only towards terminal cancer patients and their families, and the national health insurance scheme covers only inpatient hospice care for said patients. **Full text:** <http://goo.gl/Aa6FL3>

German Multiple Sclerosis Society

Evaluation of a palliative and hospice care telephone hotline for severely affected multiple sclerosis patients and their caregivers

EUROPEAN JOURNAL OF NEUROLOGY | Online – 19 September 2017 – The hotline was designed in cooperation with the German Multiple Sclerosis (MS) Society. Self-disclosed information given by callers was documented using case report forms supplemented by personal notes. 222 calls were documented in 27 months. Patients' ... mean illness duration was 18 years... Inquiries included information on palliative and hospice care (PHC), and access to PHC, general care for MS, emotional support in crisis. 31.1% of callers reported "typical" palliative symptoms (e.g., pain 88.4%), 50.5% symptoms evolving from MS, and 35.6% psychosocial problems. For 67 callers (30.2%), PHC services were recommended as indicated. The hotline provides insight into needs and problems of patients severely affected by MS and their caregivers, some of which may be met by PHC. Future follow-up calls will demonstrate if the hotline helps improve access to PHC beyond providing information. Overall, the hotline seems to be easily accessible for severely affected MS patients whose mobility is limited. **Abstract:** <https://goo.gl/SBPogk>

Charlie Gard and the limits of parental authority

THE HASTINGS REPORT, 2017;47(5):15-16. The parents of Charlie Gard, who was born 4 August 2016, with an exceedingly rare and incurable disease called mitochondrial DNA depletion syndrome, fought a prolonged and heated legal battle to allow him access to experimental treatment that they hoped would prolong his life and to prevent his doctors from withdrawing life-sustaining care. Charlie's clinicians at the Great Ormond Street Hospital in London believed that the brain damage Charlie had suffered as a result of frequent epileptic seizures, along with many other severe disabilities, would render any innovative therapy futile, and they disagreed with his parents' wishes to use an experimental therapy. They felt it in Charlie's best interest that he be allowed to die. A battle ensued among Charlie's parents, his doctors, and a guardian who had been appointed to represent him that drew the attention of politicians and prominent persons from all over the world. The case was much in the news over the past year, but it has also been frequently misunderstood. **Abstract:** <https://goo.gl/phCSN2>

N.B. Selected articles/reports on the Charlie Gard case are noted in the 31 July 2017 and 7 August 2017 issues of Media Watch (#523, p.5, #524, p.7, respectively).

Cont.

Related

- *NATIONAL CATHOLIC BIOETHICS QUARTERLY*, 2017;17(2):261-273. **'Is medical futility an ethical or clinical concept?'** The concept of medical futility first appeared at the end of the 1980s, was developed throughout the 1990s, and now is widely cited in medical literature and clinical practice to justify refraining from or limiting the use of life-sustaining therapies. The definition of medical futility, however, is not very clear or universally accepted. The authors examine the strengths and limitations of a particular concept of medical futility, based exclusively on clinical considerations, that enables the physician to make unilateral decisions about whether to withhold, withdraw, or continue treatment without being required to consult the patient or his family. To respect the patient's spiritual, philosophical, and ethical values, several significant ethical issues need to be narrowly defined, and the concept of medical futility must be rarely invoked to justify such unilateral decisions. **Abstract:** <https://goo.gl/74btr3>

N.B. Additional articles on medical futility are noted in the 26 June 2017 issue of *Media Watch* (#518, p.8).

Do we have medical measures that attest to the effect of spiritual care in time of illness

HAREFUAH, 2017;156(8):502-506. Everyone has spiritual resources that generally serve them well, and in times of struggle, part of people's suffering is spiritual. Tending to patients' "whole pain" must include their spiritual pain. Studies from Israel and worldwide found that approximately one-third of advanced cancer patients suffer spiritual distress. In addition, over half of cancer patients attach great importance to feeling hopeful, coping peacefully, and finding meaning in times of illness. Studies found a significant predictive correlation among advanced cancer patients between spiritual wellbeing and despair, desire to die, and suicidal ideation, and a longitudinal connection among patients with heart disease between survival rates and spiritual wellbeing. Spiritual care (SC) is provided in thousands of hospitals worldwide, and in limited fashion in over ten hospitals in Israel. By the nature of SC, it is difficult to clinically measure its full impact on and contribution to patients and family members. Nonetheless, studies have found a correlation between a hospital's providing SC, lowered mortality rates in the hospital and increased use of hospice care. Receipt of SC correlated with higher quality of life at the end of life. When the staff, including the SC provider, attends to patients' spirituality, studies find a substantial reduction in aggressive medical interventions at the end of life. **Abstract:** <https://goo.gl/Kjw4x5>

N.B. Article published in Hebrew.

A crisis in care for people with lung disease

THE HIPPOCRATIC POST | Online – 20 September 2017 – People who are dying from interstitial lung disease (ILD) are wasting the precious time they have left finding their way around an ineffective and unnecessarily complicated healthcare system. That's according to a report by the British Lung Foundation.¹ The report focuses on the most common ILD, idiopathic pulmonary fibrosis. A condition, with an average life expectancy of just three years after diagnosis, which affects around 32,000 people in the U.K. According to the study, many patients say their GP doesn't understand their disease and that they haven't had any clear information to help them live the short life they have left; diagnosis was delayed and in some cases dismissed. Crucially, access to vital treatments are out of reach, including drugs that could extend their life expectancy because of restrictive National Institute for Health & Care Excellence (NICE) guidelines.

A map for better care outlines the progress that has been made, identifies areas for improvement, and makes several recommendations. **Full text:** <https://goo.gl/5SKzZt>

Extract from British Lung Foundation report

Health Service trusts about their approach to PC. Of those that answered, some said that GPs would make the referral to PC; some had PC as part of their patient pathway; and, some addressed PC on a case-by-case basis. Many patients have reported that they have not even been assessed for PC. Some patients interviewed identified a "general lack of understanding of the condition's progression by GPs and others, and a lack of available services to support patients and their families at the EoL". It is clear that national bodies need to ensure there is a standardised and clear route to PC for all patients.

Cont.

1. 'A map for better care: Making effective care pathways for people with interstitial lung disease (ILD), highlights the crises in ILD care,' British Lung Foundation, September 2017. **Download/view report at:** <https://goo.gl/RVa8GL>

Related

- *CLINICAL PULMONARY MEDICINE*, 2017;24(5):206-214. '**Palliative management and end-of-life care in non-malignant advanced lung disease.**' The integration of palliative care (PC) in disease management has been shown to decrease symptom burden, improve quality of life, and reduce medical costs at the end of life (EoL), highlighting a significant need in the advanced lung disease (ALD) population. However, when comparing patients with lung cancer to those with ALD, there is a clear disparity in the use of palliative services in ALD patients. Some of the barriers to providing palliative services in ALD are ambiguous disease trajectories, and poor communication between physicians and their patients. All health care providers caring for patients with ALD, especially pulmonologists, should be confident integrating early PC measures in this patient population. This article aims to discuss the major components and barriers involved in the palliative management and EoL care in ALD. **Abstract:** <https://goo.gl/W7FBvT>

N.B. Additional articles on end-of-life care for patients living with lung cancer are noted in the 8 May 2017 issue of Media Watch (#511, pp.7-8).

End-of-life practice patterns at U.S. adult cystic fibrosis care centers: A national retrospective chart review

JOURNAL OF CYSTIC FIBROSIS | Online – 13 September 2017 – The authors reviewed 248 deaths from 71 cystic fibrosis (CF) care centers. Median age at death was 29 years... While median FEV1 was in the severe lung disease category ... 38% had mild or moderate lung disease in the year preceding death. The most common location of death was the intensive care unit ... and 12% of decedents were listed for lung transplant. Fewer of those dying in the ICU personally participated in advance care planning (ACP) or utilized hospice or palliative care (PC) services... Adults dying with CF in the U.S. most commonly die in an ICU, with limited and variable use of hospice and PC services. PC and ACP are recommended as a routine part of CF care. **Abstract:** <https://goo.gl/iWo9DB>

N.B. Additional articles on end-of-life care for people living with cystic fibrosis are noted in the 10 July 2017 issue of Media Watch (#520, p.11).

The effect of communication skills training for generalist palliative care providers on patient-reported outcomes and clinician behaviors: A systematic review and meta-analysis

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2017;54(3):404-416. This systematic review is the first to comprehensively examine the effectiveness of end-of-life care (EoLC) communication skills training interventions for generalist palliative care providers. Evidence regarding the impact of EoLC communication skills training on patient-reported outcomes was inconclusive. Training interventions do appear to be effective at improving physicians' ability to show empathy and discuss emotions. However, the effects of training on clinicians' behaviors during simulated interactions are not reflected in their behaviors when interacting with real patients, with no effect found in the latter. Although in most cases this finding was across different studies using different measures, this pattern is present in the work by *Liénard et al* and *Delvaux et al* in which the same measures were administered to the same participants in both simulated and real patient interactions.^{1,2,3} Measurement during simulated interactions might overestimate clinicians' skills, or skill levels during interactions with real patients might be more difficult to change or measure.

Full text: <https://goo.gl/gzH1Af>

1. 'Is it possible to improve residents breaking bad news skills? A randomised study assessing the efficacy of a communication skills training program,' *British Journal of Cancer*, 2010;103(2):171-177. **Full text:** <https://goo.gl/shXWTq>

Cont.

2. 'Transfer of communication skills to the workplace during clinical rounds: Impact of a program for residents,' *PLoS One*, published online 26 August 2010. **Full text:** <https://goo.gl/Yq7cQW>
3. 'Effects of a 105 hours psychological training program on attitudes, communication skills and occupational stress in oncology: A randomised study,' *British Journal of Cancer*, 2004;90(1):106-114. **Full text:** <https://goo.gl/9nKK93>

Noted in Media Watch 3 July 2017 (#519, p.3):

- U.S. | *The Los Angeles Times* – 27 June 2017 – '**I learned how to break bad news to patients and loved ones more from business school than medical school.**' A recent study of medical curricula¹ ... found the average time dedicated to end-of-life care is 13 hours spread across multiple courses over four years. In a recent survey of graduating medical students,² 42% reported that they were never taught how to talk to patients about dying, and 48% reported that they never received feedback on how they deliver bad news. No doubt this is one reason why so many people have personal stories of the "I can't believe my doctor said that to me" variety. <https://goo.gl/GceX5t>
 1. 'A 40-year history of end-of-life offerings in U.S. medical schools: 1975-2015,' *American Journal of Hospice & Palliative Medicine*, published online 10 March 2016. [Noted in Media Watch 14 March 2016 (#453, p.8)] **Abstract:** <http://goo.gl/pa3cCV>
 2. 'Determinants of medical students' perceived preparation to perform end-of-life care, quality of end-of-life care education, and attitudes toward end-of-life care,' *Journal of Palliative Medicine*, 2010;13(3): 319-326. **Abstract:** <https://goo.gl/dVH9VH>

Provider-prioritized domains of quality in pediatric home-based hospice and palliative care: A study of the Ohio Pediatric Palliative Care & End-of-Life Network

JOURNAL OF PALLIATIVE MEDICINE | Online – 22 September 2017 – Children receiving hospice and palliative care (HPC) differ from adults in important ways. Children are more likely to have rare diagnoses, less likely to have cancer, have longer lengths of stay on hospice, and are more likely to be technology dependent than adults. The [U.S.] National Consensus Project for Quality Palliative Care established domains of quality for HPC, but these domains have not been evaluated for applicability in children. Providers from the Ohio Pediatric Palliative Care & End-of-life Network were surveyed. There was strong consensus on the applicability of each domain to the participants' practices. Consensus on the rank importance of the eight domains was not achieved. Qualitative data included challenges with NCP domain 3 (Psychological & Psychiatric Aspects of Care). It was recommended that titles should remain consistent with adult standards, but domain definitions should be broadened for pediatric home-based hospice and palliative care HBHPC. Continuity and coordination of care should be added as a ninth domain of quality in pediatric HBHPC. Future studies are needed to evaluate parent- and patient-prioritized domains of quality in pediatric HBHPC and to validate and map pediatric-specific indicators to these domains. **Abstract:** <https://goo.gl/VdLY16>

N.B. National Consensus Project for Quality Palliative Care, National Coalition of Hospice & Palliative Care: <https://goo.gl/RjJmBq>. Additional articles on pediatric home-based hospice and palliative care are noted in the 3 April 2017 issue of Media Watch (#506, p.12).

Distress due to prognostic uncertainty in palliative care: Frequency, distribution, and outcomes among hospitalized patients with advanced cancer

JOURNAL OF PALLIATIVE MEDICINE | Online – 18 September 2017 – The authors describe the prevalence and distribution of distress due to prognostic uncertainty among hospitalized patients with advanced cancer before palliative care (PC) consultation. They evaluate the association between this type of distress and overall quality of life (QoL) before and after PC consultation. Two hundred thirty-six participants completed the baseline assessment. Seventy-seven percent reported being at least moderately bothered by prognostic uncertainty and half reported substantial distress. Compared with others, those who were distressed by prognostic uncertainty reported poorer overall QoL before PC consultation and greater improvement in QoL following consultation. **Abstract:** <https://goo.gl/BBPmPV>

Cont.

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 September 2017 – ‘**Predictors of death in the hospital for patients with chronic serious illness.**’ Among patients with chronic illness receiving care in a multihospital healthcare system, the authors identified the following: 1) Predictors of death in any hospital; 2) Predictors of death in a hospital outside the system; and, 3) Trends from 2010 to 2015. Patients dying in the hospital who are more likely to die in an outside hospital, and therefore at greater risk for inaccessibility of advance care planning, were more likely to be less well-educated and have cancer or diabetes, fewer co-morbidities, and fewer hospitalizations. **Abstract:** <https://goo.gl/EMMYbE>
- *PSYCHO-ONCOLOGY* | Online – 18 September 2017 – ‘**Why do oncologists hide the truth? Disclosure of cancer diagnoses to patients in China: A multisource assessment using mixed methods.**’ Qualitative data among physicians and follow-up surveys among cancer patients revealed 5 reasons for the concealment of cancer diagnoses by physicians, including lack of awareness of patients’ right to knowledge, cultural influences, insufficient medical resources and training, families’ financial concerns, and the need to protect doctors from violence. There is a discrepancy between the needs of patients and those in medical practice. **Abstract:** <https://goo.gl/HDhKPZ>

End-of-life care in Canada

Law Commission of Ontario presents findings from end-of-life project

THE LAWYER’S DAILY | Online – Accessed 18 September 2017 – When it comes to discussions around end-of-life care (EoLC), the Law Commission of Ontario has found that lawyers and health care professionals need to work toward a better interprofessional relationship to benefit their clients/patients. “One of the major things we’re hearing is that health care providers are unsure about the law and lawyers and legal providers are unsure about health care. Family members and patients get stuck in the middle,” said Ryan Fritsch, the head of the law commission’s Improving the Last Stages of Life project. The ... project started in 2015 and was inspired by the Registered Nurses Association of Ontario. Fritsch said concerned members of the association approached the law commission over its misgivings of issues in EoLC and medical assistance in dying. The law commission decided to study the issue and did preliminary consultations with stakeholders that led to the release of a public discussion paper in June 2017. The law commission is in the midst of its public consultation process, having held 19 consultation events and spoken to approximately 260 participants thus far. Fritsch said the major takeaways for lawyers in this discussion process would be their role in pre-empting disputes, how they can improve practice tools in this area and wellness in their own profession. He said when pre-empting disputes lawyers should have a good understanding of the EoLC and medical assistance in dying systems. This includes understanding what people are actually going to be faced with when making these types of decisions and what kind of health care situations they’re going to be in. **Full text:** <https://goo.gl/spC2w9>



Law Commission of Ontario
Commission du droit de l'Ontario

N.B. Access to this article requires a subscription (publication website: <https://goo.gl/7KeTva>). Project website (with links to a discussion paper on the public consultations to date and reports and related documentation): <https://goo.gl/MNwaUE>.



14 October 2017

Universal health coverage and palliative care – Don’t leave those suffering behind

<https://goo.gl/diYn7i>

Dialogue between palliative care and care ethics

MÉDECINE PALLIATIVE | Online – 20 September 2017 – From the beginning, ethical reflection seems to be inherent in the approach of the palliative culture, by questioning the nature of medical care, its limits and its meaning. By emphasizing, as a real medical issue, that care for the human being is not reduced to the objectivity of the body, nor to the purpose of its healing, and by insisting on how attention to total pain is fundamentally curing, palliative care (PC) reveals an ethical and philosophical dimension. The ethics of care, a recent trend aimed at proposing a new approach to ethics, is interesting to be explored. Indeed, the notion of vulnerability, which is central to it, is questioned in the light of a reflection on work: what are the moral springs of the work of care, both for the care receivers and the caregivers, who are both confronted with a potential shared vulnerability? The authors examine the epistemological foundations of palliative culture in order to put them in dialogue with the ethics of care: are PC naturally “anchored” in care? How do the ethics of care challenge the foundations and practices of PC? By questioning the conditions, the purposes and the foundations of PC, in their everyday context, the challenge is to put into perspective and renew the ethical dimension of PC. **Abstract:** <https://goo.gl/AGcuvA>

N.B. French language article.

When cardiopulmonary resuscitation becomes harmful

NATIONAL CATHOLIC BIOETHICS QUARTERLY, 2017;17(2):235-245. Cardiopulmonary resuscitation (CPR) is a standard emergency medical procedure. Since its inception in the late 1960s, CPR has been performed on patients unless they or their proxies refuse it. However, like all medical interventions, CPR has its benefits, risks, and consequences. Although the expected benefits of the procedure often outweigh its potential harm, CPR is not always clinically appropriate, especially for the dying, who have a very small statistical chance of surviving the intervention. Just as antibiotics are not prescribed for viruses and surgeries and treatments are withheld when clinically inappropriate, CPR should not be offered as a clinical treatment when it has a very low probability of success and is thought to be futile. Health care providers have an ethical and moral responsibility to withhold clinically inappropriate CPR, even when patients or their proxies request the procedure. **Abstract:** <https://goo.gl/js3io6>

End-of-life care in Australia

The impact of community-based palliative care on acute hospital use in the last year of life is modified by time to death, age and underlying cause of death. A population-based retrospective cohort study

PLOS ONE | Online – 21 September 2017 – Rates of hospital admission during periods of receiving community-based palliative care (PC) were reduced with benefits evident five months before death and even earlier for older decedents. The mean length of hospital stay was also reduced while receiving community-based PC, mostly in the last month of life. There were 28,939 acute care overnight hospital admissions recorded in the last year of life, an average of 2.3 per decedent and a mean length of stay of 9.2 days. Overall, the rate of hospital admissions was reduced 34% and the mean length of stay reduced 6% during periods of time decedents received community-based PC compared to periods of time not receiving this care. Decedents aged <70 years receiving community-based PC showed a reduced rate of hospital admission around five months before death, whereas for older decedents the reduction in hospital admissions was apparent a year before death. All decedents who were receiving community-based PC tended towards shorter hospital stays in the last month of life. Decedents with neoplasms had a mean length of stay three weeks prior to death while not receiving community-based PC of 9.6 days compared to 8.2 days when receiving community-based palliative care. **Full text:** <https://goo.gl/UYSvqu>

Occupational therapy

What is important to patients in palliative care? A scoping review of the patient's perspective

SCANDINAVIAN JOURNAL OF OCCUPATIONAL THERAPY | Online – 22 September 2017 – The research conducted in palliative care (PC) is often medically oriented. There are few studies clarifying the patient's preferences, priorities and desires in PC. The occupational therapy research conducted mostly concerns occupational therapy interventions based on the profession's experiences. Seventeen articles were included in the review and they were based on interviews. The theme "continuing occupational participation is important for people at the end of life" was identified. This included five sub-themes: maintaining previous occupational patterns; feeling needed; being involved in the social environment; leaving a legacy; and, living as long as you live. The results show that continued occupational participation is important for people in PC. **Abstract:** <https://goo.gl/W3mQvJ>

N.B. Additional articles on the role of occupational therapy in end-of-life care are noted in the 28 November 2016 issue of *Media Watch* (#489, p.6).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *ANNALS OF INTERNAL MEDICINE* | Online – 19 September 2017 – '**Ethics and the legalization of physician-assisted suicide: An American College of Physicians position paper.**' As a proponent of patient-centered care, the American College of Physicians (ACP) is attentive to all voices, including those who speak of the desire to control when and how life will end. However, the ACP believes that the ethical arguments against legalizing physician-assisted suicide (PAS) remain the most compelling. On the basis of substantive ethics, clinical practice, policy, and other concerns articulated in this position paper, the ACP does not support legalization of PAS. It is problematic given the nature of the patient-physician relationship, affects trust in the relationship and in the profession, and fundamentally alters the medical profession's role in society. Furthermore, the principles at stake in this debate also underlie medicine's responsibilities regarding other issues and the physician's duties to provide care based on clinical judgment, evidence, and ethics. Society's focus at the end of life (EoL) should be on efforts to address suffering and the needs of patients and families, including improving access to effective hospice and palliative care. The ACP remains committed to improving care for patients throughout and at the EoL. **Full text:** <https://goo.gl/GLQPyi>

Commentaries on ACP's position paper

- *ANNALS OF INTERNAL MEDICINE* | Online – 19 September 2017 – '**Physician-assisted suicide: Finding a path forward in a changing legal environment.**' Imagine yourself with a disease that has recently become terminal. What kinds of treatments and options would be most important to you? Almost everyone would want to be sure their physicians had considered, if not tried, all potentially effective disease-directed therapy and best possible palliative treatments to maximize their quantity and quality of life. Many patients would want to consider a timely transition to hospice care if no acceptable disease-directed therapies existed, hoping to live as fully as possible for their remaining time, and then to die peacefully. On these points we are completely in sync with the American College of Physicians position paper. **Abstract:** <https://goo.gl/xzbMtw>
- *ANNALS OF INTERNAL MEDICINE* | Online – 19 September 2017 – '**The slippery slope of legalization of physician-assisted suicide.**' Among other achievements, the ACP's paper identifies "euthanasia" and "medical assistance in dying" as euphemisms. These terms do what euphemisms are supposed to do: make a distasteful subject palatable, or at least discussable. The social process of change in ethical and moral standards makes bold use of such euphemisms. At one time, "mercy killing" and physician-assisted suicide were both illegal and unthinkable. However, times are changing, and the changes have followed a recognizable pattern. First, the unthinkable becomes discussable although highly controversial. After a while, it is seen as acceptable under certain circumstances. As it becomes more familiar, it seems increasingly sensible and reasonable. Finally, it is established as a legal right. In this way, what was once unthinkable can eventually become policy, or even a duty. **Abstract:** <https://goo.gl/L62sGJ>

Cont.

- *ANNALS OF INTERNAL MEDICINE* | Online – 19 September 2017 – ‘**Oregon’s Death With Dignity Act: 20 years of experience to inform the debate.**’ Twenty years ago, Oregon voters approved the Death With Dignity Act, making Oregon the first state in the U.S. to allow physicians to prescribe medications to be self-administered by terminally ill patients to hasten their death. This report summarizes the experience in Oregon, including the numbers and types of participating patients and providers. These data should inform the ongoing policy debate as additional jurisdictions consider such legislation. **Abstract:** <https://goo.gl/HW24yg>
- *THE HASTINGS REPORT*, 2017;47(5):30-42. ‘**Physician-assisted death and severe, treatment-resistant depression.**’ Should people suffering from untreatable psychiatric conditions be eligible for physician-assisted death? This is possible in Belgium and The Netherlands, where physician-assisted death (PAD) for psychiatric conditions is permitted, though rare, so long as the criteria of due care are met. Those opposed to all instances of PAD point to Belgium and The Netherlands as a dark warning that once PAD is legalized, restricting it will prove impossible because safeguards, such as the requirement that a patient be terminally ill, will inevitably be eroded or discarded. However, some supporters respond that limiting PAD to those suffering from terminal illness, or physical illnesses generally, is arbitrary and illogical. In addition, precisely because such patients are not terminally ill, their suffering may last for years, even the rest of their lives. Finally, severe depression may not be treatable. If PAD is justifiable under some conditions ... then why wouldn’t it be justifiable for these patients? Why shouldn’t psychiatrists who have nothing else to offer their suffering patients be able to help them to die, if that is what they want? **Abstract:** <https://goo.gl/8kfNpe>
- *NATIONAL CATHOLIC BIOETHICS QUARTERLY*, 2017;17(2):247-257. ‘**Lessons from recent polls on physician-assisted suicide.**’ Physician-assisted suicide (PAS) is an active political issue, and recent polls have indicated shifts in public opinion in favor of its permissibility and moral acceptability. However, structural errors and biasing effects exist in these polls, including several subtle logical fallacies as well as cognitive and reporting biases. Analysis of the polls suggests that public support for PAS is more conditional and much softer than the popular news headlines indicate. An understanding of how these factors function beneath the headlines provides important lessons for the discussion of PAS. **Abstract:** <https://goo.gl/YfcfpH>

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Media Watch: Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/nZMuK7>

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

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

PALLIMED: <http://goo.gl/7mrqMQ>

[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole']

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/XO4mD>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLqxy2>
[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: <http://goo.gl/o7kN3W>
[Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d1I9K>

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

Barry R. Ashpole
Guelph, Ontario CANADA

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