

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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Developing basic palliative care skills: Scroll down to [Specialist Publications](#) and 'How are physicians delivering palliative care? A population-based retrospective cohort study describing the mix of generalist and specialist palliative care models in the last year of life' (p.10), in *Palliative Medicine*.

Canada

Health Minister Gaétan Barrette defends assisted-dying law, denies cuts to palliative care

QUEBEC | *The Montreal Gazette* – 12 June 2018 – Barrette denied ... that some patients in the province are opting for medical assistance in dying because they don't have access to palliative care (PC). "It is important to note that there have been no cuts or budget pressures in PC," Barrette's press attaché, Catherine W. Audet, told *The Montreal Gazette*... "It would be false to put forward such a hypothesis." Barrette's office released the statement hours after a group of 10 Montreal-area physicians held a news conference claiming that Quebec's financially-strapped health network is forcing some patients to accept assisted dying because they can't find adequate PC. "Patients end up wanting to die because they do not have access to proper medical care," Dr. Paul Saba, who is challenging Quebec's assisted-dying law in court, told reporters. Saba cited a 29 May letter by the Quebec College of Physicians to Barrette expressing concerns of an "absence of medical shifts in several PC units, which could compromise care." The College urged Barrette to boost PC resources "without delay." Saba argued that the provincial government is not respecting its own law by effectively denying patients the right to informed consent because access to PC is spotty at best. <https://goo.gl/gwbrVU>

Extracts from *The Montreal Gazette* article

638 terminally-ill Quebecers died in 2016-2017 as a result of a lethal injection administered by a doctor, up from 167 the year earlier. Doctors rejected a total of 377 requests.

The number of people in Quebec who have received palliative care at home rose to nearly 24,000 in 2017-2018 from almost 22,000 four years earlier.

Specialist Publications

'End-of-life strategies among patients with advanced chronic obstructive pulmonary disease' (p.6), in *American Journal of Respiratory & Critical Care Medicine*.

Journal Watch

'Open access journals and predatory publishing in palliative care' (p.13), in *Medicina Paliativa*.

Cont.

Noted in Media Watch 4 June 2018 (#566, p.2):

- QUEBEC | CBC News (Montreal) – 31 May 2018 – **‘Lack of palliative care pushing Quebecers toward medically assisted death, College of Physicians says.’** A lack of palliative care (PC) services in parts of Quebec may be forcing patients to choose medical aid in dying (MAiD) as a way to end their lives with dignity, says Quebec’s College of Physicians. In a letter sent to Quebec Health Minister Gaétan Barrette, the group said Quebec is suffering from a lack of specialized, PC doctors and uneven levels of service are being offered across the province. The college said patients requesting MAiD are getting priority access to available resources, “to the detriment of other patients” at the end of their lives. “PC cannot be limited to access to MAiD,” its letter reads. The group’s president, Dr. Charles Bernard, said fewer physicians and medical professionals have chosen to specialize in PC over the last two years. <https://goo.gl/bcvvy1>

[U.S.A.](#)

That “living will” you signed? At the ER, it could be open to interpretation

KAISER HEALTH NEWS | Online – 14 June 2018 – Unfortunately, misunderstandings involving documents meant to guide end-of-life (EoL) decision-making are “surprisingly common,” said Dr. Monica Williams-Murphy, medical director of advance-care planning and EoL education for Huntsville Hospital Health System in Alabama. But health systems and state regulators don’t systematically track mix-ups of this kind, and they receive little attention amid the push to encourage older adults to document their EoL preferences, experts acknowledge. As a result, information about the potential for patient harm is scarce. A new report out of Pennsylvania, which has the nation’s most robust system for monitoring patient safety events, treats mix-ups involving EoL documents as medical errors – a novel approach.¹ It found that in 2016, Pennsylvania health care facilities reported nearly 100 events relating to patients’ “code status” – their wish to be resuscitated or not, should their hearts stop beating and they stop breathing. In 29 cases, patients were resuscitated against their wishes. In two cases, patients weren’t resuscitated despite making it clear they wanted this to happen. The rest of the cases were “near

misses” – problems caught before they had a chance to cause permanent harm. Most likely, this is an undercount since reporting was voluntary, said Regina Hoffman, executive director of the Pennsylvania Patient Safety Authority, adding that she was unaware of similar data from any other state. <https://goo.gl/EjXiNy>

[Specialist Publications](#)

‘Don’t shoot the messenger: Experiences of delivering prognostic information in the context of advanced cancer’ (p.5), in *American Journal of Hospice & Palliative Medicine*.

‘Nursing home residents’ legal access to onsite professional psychosocial care [in the U.S.]: Federal and state regulations do not meet minimum professional social work standards’ (p.7), in *The Gerontologist*.

‘Palliative care: Who is responsible?’ (p.10), in *Journal of the National Comprehensive Cancer Network*.

1. ‘Empowering Patients and Agents to Help Prevent Errors with Living Wills, DNRs, and POLSTs,’ Pennsylvania Patient Safety Authority, June 2018. **Download/view at:** <https://goo.gl/YvkHJi>

Cont. next page

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

- PENNSYLVANIA | *The Inquirer* (Philadelphia) – 16 February 2017 – **‘Doctors are confused by living wills, study finds.’** Interpreting a living will is, by definition, a life-and-death activity. So, it’s not comforting that, when hundreds of doctors were asked to decide what nine different living wills and related documents meant, they rarely agreed. In a new study,¹ the doctors reached consensus – defined as 95% agreement – on only two of the scenarios. If they read the papers and also saw a one-minute video of a patient describing his or her wishes, they agreed on how to treat a third case and reached 94% agreement on a fourth. <https://goo.gl/TqJGA1>
 1. ‘Nationwide multicenter evaluation to determine whether patient video testimonials can safely help ensure appropriate critical versus end-of-life care,’ *Journal of Patient Safety*, published online 14 February 2017. **Abstract:** <https://goo.gl/8oKujE>

Related

- LEXOLOGY | Online – 14 June 2018 – **‘To resuscitate or not: the legal issues with DNR tattoos.’** Although most frequently seen on a physical document, there are also tattoos stating ‘Do Not Resuscitate’ or sometimes it is simply the letters ‘DNR’ on a person’s chest. People believe that these tattoos (compared to paperwork and medical bracelets) cannot be misplaced, removed or lost. Emergency responders are also unlikely to miss a tattoo on a person’s chest when attempting to resuscitate. Although a patient may see these tattoos as adding clarity to their convictions, these tattoos are presenting confusion for doctors and emergency responders. <https://goo.gl/wybonw>

New Jersey policy group releases blueprint for improving end-of-life care

NEW JERSEY | NJ Spotlight (Montclair) – 12 June 2018 – With more than 25% of New Jerseyans dying in hospitals, rather than in their own homes, improving end-of-life care (EoLC) should be a priority. And it is one that can be achieved through some targeted investments, according to a well-respected healthcare consultancy – such as developing a state-wide database to keep residents’ requests and wishes readily accessible. The group also called for higher reimbursements for treatment consultations and palliative care, and better education both for healthcare providers and for the public at large. The recommendations were part of a strategic plan for EoLC released by the non-profit New Jersey Health Care Quality Institute and funded by The Nicholson Foundation, which seeks to expand access to care for vulnerable populations.¹ The report outlines ways in which state officials can work with hospitals, medical schools, local communities, and other groups to provide more appropriate – and often less expensive – medical treatments and support services to patients nearing the end. <https://goo.gl/P9SNxH>



1. ‘End-of-Life Care Strategic Plan for New Jersey,’ New Jersey Health Care Quality Institute, June 2018. **Download/view at:** <https://goo.gl/rEWRQh>

Noted in Media Watch 4 September 2017 (#528, p.3):

- NEW JERSEY | *The Teaneck Daily Voice* – 1 September 2017 – **‘\$5 million appropriation will fund end-of-life care model in New Jersey.’** The budget appropriation will support eight key initiatives, including the development of a model for end-of-life (EoL) care in New Jersey, which will address every aspect of care in the two years leading up to a person’s death and the 12 months following a person’s death. Other initiatives include the development of education, training, and state certification courses for doctors, nurses, social workers, and other healthcare professionals; research comparing EoL experience and quality of life for those enrolled and not enrolled in hospice programs; and, policy recommendations in partnership with the Medical Society of New Jersey. According to the Dartmouth Atlas of Health Care Report,¹ New Jersey is ranked lower than any other state in the nation in the use of hospice and palliative care. <https://goo.gl/8w7CJN>
 1. ‘Tracking Improvement in the Care of Chronically Ill Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life,’ The Dartmouth Institute for Health Policy & Clinical Practice, Lebanon, New Hampshire, June 2013. [Noted in the 11 June 2013 issue of Media Watch (#310, p.4)] **Download/view at:** <http://goo.gl/aRxuH6>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | Court News Service (Pasadena) – 15 June 2018 – ‘**California State Appeals Court reinstates right-to-die law**.’ A California appellate court temporarily reinstated the state’s End of Life Option Act, which allows terminally ill patients to receive physician-assisted suicides. The law was deemed unconstitutional last month by a state court judge who said lawmakers acted outside the scope of their authority by passing it during a special session convened by Governor Jerry Brown to discuss health care issues. In 2017, Riverside County Superior Court Judge Daniel Ottolia advanced a lawsuit filed by Life Legal Defense Foundation on behalf of a group of California-based doctors and the American Academy of Medical Ethics doing business as Christian Medical & Dental Society, who sought an injunction against the law because they claimed it violated the state’s constitution. The Riverside District Attorney and California Attorney General were named in the suit, which was filed the day before the law went into effect in 2016. Last month, Ottolia agreed the law did not fall within the scope of access to health care services, and ruled suicide should not be considered a medical service. He stayed his ruling, issued from the bench, to give the state time to appeal. <https://goo.gl/uuGKCW>
- THE WASHINGTON POST | Online – 11 June 2018 – ‘**American Medical Association to keep reviewing its opposition to assisted death**.’ A recommendation that the American Medical Association (AMA) maintain its opposition to medically assisted death was rejected, with delegates at the AMA’s annual meeting instead voting for the organization to continue reviewing its guidance on the issue. Following a debate on whether the nation’s most prominent doctors’ group should revise its Code of Medical Ethics, the House of Delegates voted by a margin of 56 to 44 percent to have the AMA’s Council on Ethical & Judicial Affairs keep studying the current guidance. That position, adopted a quarter-century ago, labels the practice “physician-assisted suicide” and calls it “fundamentally incompatible with the physician’s role as healer.” The council spent two years reviewing resolutions, not so much on whether to support the practice but on whether to take a neutral stance on what has become a divisive issue among health-care providers. The group’s report sought to find common ground, noting, “Where one physician understands providing the means to hasten death to be an abrogation of the physician’s fundamental role as healer that forecloses any possibility of offering care that respects dignity, another in equally good faith understands supporting a patient’s request for aid in hastening a foreseen death to be an expression of care and compassion.” <https://goo.gl/reRY19>

International

Hospice staff “trained to report dying patients as part of terror strategy”

U.K. | *The Guardian* (London) – 11 June 2018 – Doctors and nurses are being trained to monitor terminally ill people and dementia patients and their visitors for signs of radicalisation as part of the government’s Prevent scheme, *The Guardian* has learned. A senior National Health Service (NHS) whistleblower who works on the programme said that its operations in the health system were so indiscriminate that she had carried out the training in hospices and said that she knew of other trainers who had operated in dementia wards. “I have personally delivered this training in a hospice,” the whistleblower said. “The training requires staff to monitor and judge the thoughts and actions of a specific group of people and even refer them to the police without their knowledge.” Criticising Prevent’s operation in the NHS more broadly, she said: “Patients who don’t trust their doctor or nurse may not seek advice from them, which could be potentially life threatening. Prevent moves people’s focus away from care, treatment and support into areas that are police business: counter-terrorism and surveillance.” Hospice and dementia services have been caught under a blanket application of Prevent across the NHS. The disclosures will raise fresh questions over the credibility of the programme, which is designed to identify individuals who hold radical views before they commit a crime. <https://goo.gl/iLvQ4q>

Specialist Publications

Quality of primary palliative care for older people with mild and severe dementia: An international mortality follow-back study using quality indicators

AGE & AGEING | Online – 8 June 2018 – While the countries studied differ in the overall quality of primary palliative care, they have similarities in room for improvement. First, the pain of more than half of patients across countries was not regularly measured, which is comparable to what was found in long-term and acute care settings. Pain is highly prevalent among older people with dementia, and if not treated adequately may lead to depression, agitation and aggression. Even where self-reporting is not possible due to cognitive decline, other strategies can be used, such as direct observation of behavioural cues and the use of validated tools such as Pain Assessment in Advanced Dementia Scale. In line with an earlier study, more than two-thirds of patients, particularly in Italy and Spain, appeared to have poor communication with GPs. The relatively higher score for patient-GP communication in Belgium may be due to their continued efforts in advance care planning and the culture of wanting to be informed about health-related issues. While this poor communication with patient may be understandable due to cognitive decline, this study suggests that this is a problem even for people with mild dementia. Similar with an earlier study, the authors found high levels of relative-GP communication across the three countries, implying that GPs communicate more often with relatives than with patients, which seems to be an alternative to the poor communication with patients. **Full text:** <https://goo.gl/SGbPMo>

N.B. Additional articles on palliative and end-of-life care for people living with Alzheimer's and other forms of dementia noted in the 11 June 2018 issue of Media Watch (#567, p.5).

Don't shoot the messenger: Experiences of delivering prognostic information in the context of advanced cancer

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 12 June 2018 – The study of prognostic understanding is imperative as the trend toward individualized medicine continues. However, without guidelines for discussing prognosis, palliative care (PC) clinicians face challenges presenting prognostic information in a way that optimizes patient understanding, psychological adjustment, and decision-making. Fifteen oncology, psycho-oncology, and PC professionals with expertise in doctor-patient communication participated in semi-structured interviews that focused on identifying the breadth of factors underlying prognostic understanding, as well as methods to identify and quantify this understanding. Interviews yielded two types of information. Participants described the multifaceted nature of prognostic understanding and identified five distinct elements of prognostic understanding: 1) Understanding of current state of disease; 2) Life expectancy; 3) Curability; 4) Decline trajectory; and, 5) Available treatment options. Participants also offered “best practice” techniques, including methods for determining a patient's preferences for and understanding of prognostic information, assessing

patient fears and concerns, and communicating medical uncertainties. Results emphasize the need for clinicians to join with patients to ensure that prognostic information is well understood. **Abstract:** <https://goo.gl/xZqCEE>

Those numbered days: An autoethnography on living and dying with a cancer patient

JOURNAL OF HUMAN VALUES | Online – 7 June 2018 – It is a self-transforming event to see close cared for people die. Yet frequently these experiences remain unreported in academic writing. The present article attempts to depict the narratives of attachment in the context of terminal illness and detachment as a consequence of death of the research participant, Jabbar, to reflect on such a journey. It focuses on the formation of a relationship beyond the boundaries of the purposes of research to reflect on two related issues, first, the nature of attachments and relationship building that goes in parallel to the formal dimensions of the research and second, emotions, self-transformation and contextual embeddedness of doing research with terminally ill cancer patients. **Abstract (inc. list of references):** <https://goo.gl/Uqwz3g>

Cont.

Noted in Media Watch 11 June 2018 (#567, p.14):

- *CLINICAL ETHICS* | Online – 3 June 2018 – ‘**Truth-telling to a cancer patient about poor prognosis: A clinical case report in cross-cultural communication.**’ The author discusses the ethical dilemma of truth-telling and withholding information about poor prognosis. It highlights the complexities of applying ethical principles in a different cultural milieu, reflecting on different ethical frameworks and justifications. He also discusses some of the wider implications of the practices, issues and controversies of truth-telling about prognosis in cross-cultural communication relevant to clinical practice. **Abstract:** <https://goo.gl/mMyPjk>

Noted in Media Watch 4 June 2018 (#566, p.8):

- *ASCO EDUCATIONAL BOOK*, 2018;38(1):787-794. ‘‘**How much time do I have?’’: Communicating prognosis in the era of exceptional responders.**’ A robust literature shows that many patients with advanced cancer have inaccurate perceptions of their prognosis, thus raising questions about whether patients are truly making informed decisions. Clinicians’ ability to communicate prognostic information is further complicated today by the availability of novel, efficacious immunotherapies and genome-guided treatments. Currently, clinicians lack tools to predict which patients with advanced disease will achieve an exceptional response to these new therapies. **Full text:** <https://goo.gl/nqWsdh>

End-of-life care in Canada

End-of-life strategies among patients with advanced chronic obstructive pulmonary disease

AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE | Online – 11 June 2018 – A population-based repeated cross-sectional study examining end-of-life (EoL) care strategies in individuals with advanced chronic obstructive pulmonary disease (COPD) was conducted. Annual proportions of individuals who received formal palliative care (PC), long-term oxygen therapy or opioids from 2004 to 2014 were determined. There were 151,912 persons with advanced COPD in Ontario, Canada, between 2004 and 2014. Use of formal PC services increased 1% per year from 5.3% in 2004 to 14.3% in 2014, while use of long-term oxygen therapy increased 1.1% per year from 26.4% in 2004 to 35.3% in 2013. The use of opioids was relatively stable (40.0% in 2004 and 41.8% in 2014). Younger individuals were less likely to use formal PC services and long-term oxygen therapy. Males were less likely than females to receive long-term oxygen therapy and opioids. The proportion of people with advanced COPD using EoL strategies, although increasing, remains low. Efforts should focus on increasing access to such strategies as well as educating patients and providers of their benefits. **Abstract:** <https://goo.gl/89wzeT>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 June 2018 – ‘**Resource use during the last 6 months of life among COPD patients: A population level study.**’ Resource use among 13,086 patients dying of or with COPD was studied. Those who died of chronic obstructive pulmonary disease (COPD) received less opioids, sedatives and morphine, used less palliative care (PC) services, and received more invasive and non-invasive ventilation as compared to the other groups studied. Those who died of lung cancer (LC) had more specialist contacts, hospital admissions and medical imaging as compared to those who died of COPD or cardiovascular disease (CVD). Those who died of CVD used less PC services when compared to those who died of LC and had a comparable use of hospital, ICU, home care, opioids, sedatives and morphine as those who died of COPD. **Abstract (w. link to references):** <https://goo.gl/b6jqQt>

N.B. Additional articles on palliative and end-of-life care for people living with chronic obstructive pulmonary disease noted in the 26 March 2018 issue of Media Watch (#556, p.8).



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 beginning on p.14.

End-of-life care in Australia

End-of-life care of oncology inpatients: Are we getting it right?

ASIA-PACIFIC JOURNAL OF CLINICAL ONCOLOGY | Online – 13 June 2018 – At the time of death, 98% of patients [i.e., 295 consecutive adult medical oncology inpatients dying between 2010 and 2015] had a resuscitation plan, 71% of which were completed by the medical oncology team. Fifty-nine percent of medical emergency team reviews occurred in patients without a documented resuscitation plan. Within 48 hours of death, active interventions were still being given to 64% of patients in the total patient population. Comfort care plans were documented in 86% of patients; however, 62% of these were only documented within 48 hour of death and 20% of patients with a documented comfort care plan. **Abstract:** <https://goo.gl/LS9iDW>

Integrative approaches in pediatric palliative care

CHILDREN | Online – 13 June 2018 – Integrative medicine is supported by evidence and aims to heal the whole person, including all aspects of one's lifestyle. Therapies offered by integrative medicine often empower patients and families, allowing for a sense of control. This review addresses the merging of integrative medicine philosophy and modalities with the care given to children with life-limiting illness. The authors review an introduction to integrative medicine, trends in its incorporation in the healthcare setting, application to patients receiving palliative care and the management of specific symptoms. A case study is offered to illustrate these principles. **Full text:** <https://goo.gl/wurKEd>

Nursing home residents' legal access to onsite professional psychosocial care [in the U.S.]: Federal and state regulations do not meet minimum professional social work standards

THE GERONTOLOGIST | Online – 13 June 2018 – The federal government holds nursing homes (NHs) responsible for assessing and addressing resident psychosocial needs. The staff person most responsible for psychosocial care planning is the social worker. However, the federal government requires only NHs with 120+ beds to employ one full-time social worker, and that person need not hold a social work degree. The authors compare/contrast state laws against federal laws and professional standards in terms of the minimum qualifications of NH social workers to determine in which states NH residents are legally entitled to receive services from a professional social work staff member. Twelve states do not address NH social worker qualifications. Up to twenty-five appear to be out of federal compliance. Only Maine appears to meet the National Association of Social Workers' standards. Other states approaching the standards include: Alaska, Arkansas, Connecticut, Illinois, Massachusetts, Minnesota, and West Virginia. The vast majority of the three million residents a year served by U.S. NHs are not entitled to social work staff who meet minimum professional standards, despite new federal regulations calling for trauma-informed and culturally competent care planning and the recognition that the needs of residents (including psy-

chosocial needs) have continued to increase over past decades. Changes in federal regulations are recommended so that all NH residents have access to professional psychosocial services provided by a staff person who has earned at least a bachelor's degree in social work and who carries a reasonable caseload. **Abstract:** <https://goo.gl/LF9iVt>

Conversations about death and dying with older people: An ethnographic study in nursing homes

HEALTHCARE | Online – 14 June 2018 – Nursing homes are often places where older persons "come to die." Despite this, death and dying are seldom articulated or talked about. The assistant nurses [who were interviewed] used the strategies of distracting, comforting, and disregarding either when they perceived that residents' reflections on death and dying were part of their illness and disease or when there was a lack of alignment between the residents' contemplations and the concept of dying well. The study participants indicated that ambivalence and ambiguity toward conversations about death and dying should be taken into consideration in future implementations of knowledge-based palliative care that take place in nursing homes after this project is finalized. **Full text:** <https://goo.gl/Ut73sc>

Cont.

Related

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2018;21(2):41-50. '**Models for spiritual care in hospice and palliative care.**' The literature has provided ten evidence-based theories that can be used as models in hospice and palliative care (HPC). Three of the models focus on how the spiritual care outcomes of viewing spiritual health, quality of life, and coping, are important outcomes. The remaining seven models focus on implementation of spiritual care. The "whole-person care model" addresses the multidisciplinary collaboration within HPC. The "existential functioning model" emphasizes the existential needs of human beings. The "open pluralism view" considers the cultural diversity and other types of diversity of care recipients. The "spiritual-relational view" and "framework of systemic organization" models focus on the relationship between hospital palliative care teams and terminally ill patients. **Full text:** <https://goo.gl/4F6JRz>

N.B. English language article.

- *MEDICINA PALIATIVA*, 2018;25(3):203-212. '**Psychological interventions in spirituality: A systematic review in palliative care.**' The objective of this systematic review is to summarize the latest scientific evidence on spirituality in palliative patients with advanced disease, paying particular attention to the kind of intervention that addresses the spiritual dimension that has been used. This review, however, has been severely limited by the wide variability of the characteristics of the studies. There is great difficulty in selecting benchmarks, since the design of the studies is diverse, as well as the variables and testing instruments. Although interventions were found that implied an improvement in spirituality, they do not focus on the actual work on this element. All this makes an evaluation of the effectiveness of protocols on spirituality difficult and hinders access to knowledge concerning the care by health professionals of the spiritual needs of palliative patients. **Abstract:** <https://goo.gl/onL2iB>

N.B. Spanish language article.

When religion and medicine clash: Non-beneficial treatments and hope for a miracle

HEC FORUM | Online – 7 June 2018 – Differences of opinion between physicians and patients/families about what are appropriate interventions in specific clinical situations are often fraught with highly strained emotions, and perhaps none more so when the family bases their desires on religious belief. The author of this article discusses non-beneficial treatments in light of these sorts of disputes, when there is a clash between the nominally secular world of fact- and evidence-based medicine and the faith-based world of hope for a miraculous cure. He asks the question whether religious belief can justify providing treatment that has either no or a small chance of restoring meaningful function. The author concludes that non-beneficial therapy by its very definition cannot be helpful, and indeed is often harmful, to patients and hence cannot be justified no matter what the source or kind of reasons used to support its use. Therefore, doctors may legitimately refuse to provide such treatments, so long as they do so for acceptable clinical reasons. **Abstract (inc. list of references):** <https://goo.gl/SttALX>

Noted in Media Watch 30 April 2018 (#561, p.6):

- *AMERICAN JOURNAL OF BIOETHICS*, 2018;18(5):40-51. '**Responding to those who hope for a miracle: Practices for clinical bioethicists.**' The authors argue the ethicist must understand the complexity of the miracle-invocation. They provide a taxonomy of miracle-invocations that assist the ethicist in analyzing the invocator's conceptions of God, community, and self. After the ethicist appreciates how these concepts influence the invocator's worldview, she can begin responding to this hope with specific practices. **Abstract (w. link to references):** <https://goo.gl/3Qbwj8>

A Code of Practice on Advanced Healthcare Directives

THE IRISH MEDICAL TIMES | Online – 13 June 2018 – Advance Healthcare Directives (AHDs) have been introduced into Irish law as part of the Assisted Decision-Making (Capacity) Act 2015. A person with capacity – a “directive-maker” – may make an Advance Healthcare Directive that will come into effect when they lack the capacity to make healthcare treatment decisions for themselves. The Draft Code of Practice for Health & Social Care Professionals, which was published by the Health Service Executive (HSE) in March 2018, is for all health and social care professionals who are interacting with persons in relation to AHDs. There are a number of issues in the Draft Code which may cause significant medico-legal and ethical concerns to medical practitioners, the Irish Medical Organization (IMO) also warned. In relation to a functional approach to decision-making, the IMO said in order to have capacity to make a decision, a person/patient must be able to understand the information relevant to the decision to be made and be able to use and weigh up the information. This, the IMO explained, implies that the person must have some knowledge and understanding of the medical issues involved. “If the person has not consulted with a medical practitioner in creating an AHD, this may be open to challenge. The presumption of capacity without a formal assessment may leave doctors legally exposed.” **Full text:** <https://goo.gl/SWLQRf>

Related

- *FAMILY PRACTICE* | Online – 11 June 2018 – ‘**How do Dutch primary care providers overcome barriers to advance care planning with older people? A qualitative study.**’ Respondents overcame their own insufficient knowledge and skills, as well as their negative attitudes and belief, by gaining experience through practicing advance care planning (ACP) in their daily practices, exchanging and reflecting on those experiences with peers, pursuing continuing education, teaching and participating in research. To overcome patients’ and families’ lack of initiative and openness to ACP, respondents prepared them for further steps in ACP. **Abstract:** <https://goo.gl/Du4dxy>
- *BMC MEDICAL ETHICS* | Online – 11 June 2018 – ‘**Advance directive: Does the GP know and address what the patient wants? Advance directive in primary care.**’ This study shows that the majority of the citizens already heard about an advance directive (AD). Despite this, more than half of the surveyed GPs made 5 or less ADs last year. These observations confirm previous findings regarding the (low) number of signed ADs. Most GP’s provide information and schedule a follow-up consultation in agreement with the Flemish guideline for drafting ADs. The main barrier remains the time-consuming impact of these appointments. **Full text:** <https://goo.gl/RkF8CK>

Representative claims in healthcare: Identifying the variety in patient representation

JOURNAL OF BIOETHICAL INQUIRY | Online – 7 June 2018 – In many countries patient involvement is high on the healthcare policy agenda, which includes patient representation in collective decision-making. Patient organizations are generally considered to be important representatives of patients. Other actors also claim to represent patients in decision-making, such as politicians, healthcare professionals, and client advisory councils. In this article, the authors take a broad view of patient representation, examining all the actors claiming to represent patients in the Dutch debate on the decentralization of care. They conclude that variety in forms of representation could help do justice to the variety of patient preferences. In addition the authors conclude that in order to ensure the democratic quality of patient representation, actors making representative claims have to reflect on how their claims relate to each other and how they can ensure authorization and accountability in the representative relationship with those they claim to represent. **Full text:** <https://goo.gl/uim2Rk>

Noted in Media Watch 4 June 2018 (#566, p.10):

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 25 May 2018 – ‘**Representing whom? U.K. health consumer and patients’ organizations in the policy process.**’ The authors draw on nearly two decades of research on health consumer and patients’ organizations (HCPOs) in the U.K. In particular, it addresses questions of representation and legitimacy in the health policy process. HCPOs claim to represent the collective interests of patients and others such as relatives and carers. At times they also make claims to represent the wider public interest. The authors explore how and in what sense HCPOs represent their constituencies. **Abstract (inc. list of references):** <https://goo.gl/dCqqtS>

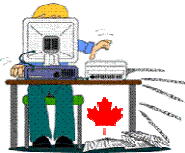
Palliative care: Who is responsible?

JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK, 2018;16(6): 791-792. In a time when medicine has been fairly criticized as producing too many subspecialists, a positive movement toward multidisciplinary care teams has begun. Oncology programs are no exception. Although many cancer centers have dedicated teams based on the primary cancer, individual members within these teams represent multiple disciplines. For example, at minimum, a head and neck cancer team should include a medical oncologist, radiation oncologist, surgical oncologist, nurse, dietitian, speech language pathologist, and social worker. For patients with advanced cancer, multiple randomized studies have shown that early palliative care (PC) improves patient quality of life, and in some instances quantity of life. Therefore, an oncology program is not complete without PC. Feldstain *et al* skillfully demonstrate not only the statistical but also the clinical benefits of interdisciplinary specialist PC in reducing symptom burden and detecting distress in patients with high intensity scores.¹ Their team consistently used two validated tools at patient encounters: the Edmonton Symptom Assessment System (ESAS) and the Canadian Problem Checklist (CPC). The ESAS is a questionnaire that asks patients to rate the severity of 9 common symptoms – pain, fatigue, tiredness, nausea, appetite, shortness of breath, depression, anxiety, and well-being – on a visual analogue scale ranging from 0 to 10. The CPC is a checklist of the most commonly reported problems, divided into the following domains of functioning: physical, emotional, social/family, spiritual, informational, and practical, although the version used by Feldstain and colleagues also included mobility. **Full text:** <https://goo.gl/QJs9XB>

How are physicians delivering palliative care? A population-based retrospective cohort study describing the mix of generalist and specialist palliative care models in the last year of life

PALLIATIVE MEDICINE | Online – 11 June 2018 – In a palliative care (PC) model where coordination of care exists between physicians, all clinicians (including family physicians, oncologists and other medical and surgical specialists) should have the basic PC skill sets to provide “generalist palliative care.” Specialists should have skills for managing more complex and difficult cases, providing “specialist palliative care.” PC specialists should support generalists through consultation PC and transfer of care (i.e., care transferred prior to death to a specialist PC physician) where indicated. Research using health administrative databases can provide important insights into the models of physician-based PC. The authors operationalized a physician-based PC model as: low engagement (i.e., no physician PC services), generalist PC only, consultation PC (i.e., generalist and specialist PC) and specialist PC only. In a large population-level decedent cohort in Ontario, Canada, the authors show that most decedents (53.0%) received no physician-based PC, while only 14.7% received consultation PC. PC specialists reached only 25.8% of all decedents. Only 37.5% of practicing physicians delivered PC. Nearly three-quarters (74.2%) of PC is provided by family physicians, who either have a generalist or specialist PC focus of practice. **Full text:** <https://goo.gl/cQqsfu>

1. ‘Outcomes from a patient-centered, interprofessional, palliative consult team in oncology,’ *Journal of the National Comprehensive Cancer Network*, 2018;16(6):719-726. **Abstract:** <https://goo.gl/6Z746a>



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>

The views of homeless people and healthcare professionals on palliative care and the desirability of setting up a consultation service: A focus group study

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 June 2018 – Palliative care (PC) for homeless people is especially complex and differs substantially from regular PC. It differs greatly between professionals, institutions and cities. Homeless people get less autonomy than they would like. Homeless people and professionals have different perceptions of the care provided. Trusting relationships between professionals and homeless people are essential, and easily accessible, and flexible care is needed. Consultation, in particular involving exchange of expertise between professionals, can provide added value to professionals. Homeless people consider consultation primarily as an opportunity to train professionals to show more understanding, provide tailored PC and enhance professional collaboration. The local situation, characteristics of a consultant and role of a consultant in providing information and education must be considered when developing the consultation process. **Abstract:** <https://goo.gl/hPz6z2>

European Journal of
Palliative Care 
A JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

The homeless: a vulnerable population with poor access to palliative care

■ In his regular column, **Barry Ashpole** presents a selection of abstracts that highlight new findings and trends in the diverse and rapidly expanding body of research in the field of palliative and end-of-life care.

See March/April issue of the *European Journal of Palliative Care* (p.89). Access requires a subscription.
Contents page: <https://goo.gl/7w8HS9>

Race/ethnicity, socioeconomic status, and healthcare intensity at the end of life

JOURNAL OF PALLIATIVE MEDICINE | Online – 12 June 2018 – Although racial/ethnic minorities receive more intense, non-beneficial healthcare at the end of life, the role of race/ethnicity independent of other social determinants of health is not well understood. The authors identified 22,068 decedents with chronic illness cared for at a single healthcare system in Washington State who died between 2010 and 2015 and linked electronic health records to death certificate data. They examined three measures of healthcare intensity: 1) Intensive care unit admission; 2) Use of mechanical ventilation; and, 3) Receipt of cardiopulmonary resuscitation. Minority race/ethnicity, lower income and educational attainment, and Medicaid and military insurance were associated with higher intensity care. Socioeconomic disadvantage accounted for some of the higher intensity in racial/ethnic minorities, but most of the effects were direct effects of race/ethnicity. **Abstract:** <https://goo.gl/MQsakF>

Ambulance staff and end-of-life hospital admissions: A qualitative interview study

PALLIATIVE MEDICINE | Online – 11 June 2018 – Hospital admissions for end-of-life (EoL) patients, particularly those who die shortly after being admitted, are recognised to be an international policy problem. How patients come to be transferred to hospital for care, and the central role of decisions made by ambulance staff in facilitating transfer, are under-explored. Ambulance interviewees were broadly positive about enabling people to die at home, provided they could be sure that they would not benefit from treatment available in hospital. Barriers for non-conveyance included difficulties arranging care particularly out-of-hours, limited available patient information and service emphasis on emergency care. Ambulance interviewees fulfilled an important role in the admission of EoL patients to hospital, frequently having to decide whether to leave a patient at home or to instigate transfer to hospital. Their difficulty in facilitating non-hospital care at the EoL challenges the negative view of near EoL hospital admissions as failures. Hospital provision was sought for dying patients in need of care which was inaccessible in the community. **Full text:** <https://goo.gl/33uoVZ>

Cont.

Related

- *JOURNAL OF PARAMEDIC PRACTICE* | Online – 12 June 2018 – ‘**End-of-life care in the community: The role of ambulance clinicians.**’ This article presents an overview of some of the issues that impact on the delivery of care to patients at the end of life (EoL), including symptom and urgent care needs in the last few days of life; preferences for care/place of care; and, coordination of care. The authors outline an online education package in EoL care, which has been specifically designed for ambulance clinicians in response to an analysis of their training needs. **Abstract:** <https://goo.gl/oqj9yF>

Exploring the lived experience of migrants dying away from their country of origin

QUALITY OF LIFE RESEARCH | Online – 12 June 2018 – Migrants experience challenges settling into a new society, while retaining their cultural and religious values. Concurrently facing an end-of-life illness can result in existential distress affecting quality of dying. This study aimed to explore the lived experience of migrants dying away from their country of birth or origin. Three notions emerged. The first was dual possession of a new hybrid identity developed in their adoptive country, and an inner ethnic and cultural identity, in varying degrees of harmony with each other. The second was being in life review – reliving homeland memories and letting go of dreams. The third notion showed how they sought resolution by enacting continuity through their children, hoping for a final homeland visit, or conveying their dying wishes. How life review was enacted for each migrant and resolution depended on finding some degree of belonging in their country of adoption. Implications for end-of-life care include education to increase practitioner awareness and use of formal and informal life review. Enhancing spiritual well-being can assist resolution of end-of-life adjustment. **Abstract (inc. list of references):** <https://goo.gl/dbmKyq>

N.B. Selected articles on repatriation to their homeland of patients living with a terminal illness noted in the 28 November 2016 issue of Media Watch (#489, pp.15-16).

End-of-life care in Brazil

End-of-life paradigm in medical training: Attitudes and knowledge about death and palliative care

REVISTA BRASILEIRA DE EDUCAÇÃO MÉDICA, 2018;42(2). In Brazil, palliative medicine has recently been promoted to the category of medical specialty, obliging Brazilian medical schools to review the educational concepts associated to end-of-life (EoL) care. The personal relationship with death seems to directly influence the premise of care-more-than-healing, as an essential element of the caregiver's relationship with the terminal patient. There is a close relationship between anxiety and fear of death and the medical student's attitude in the face of EoL situations. The scholar's view of death may determine their inner disposition, values, concepts, and prejudices regarding death and dying and determine their performance as a professional. Thus, medical education programs must emphasize not only the theoretical-technical aspects in palliative care, but also the emotional climate that involves the medics' attitudes and actions in EoL situations. **Full text:** <https://goo.gl/d2ghrQ>

N.B. Portuguese language article.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BRITISH MEDICAL JOURNAL* | Online – 15 June 2018 – ‘**Swiss doctors object to new suicide guidance.**’ Leading doctors in Switzerland are objecting to new guidelines issued by the Swiss Academy of Medical Sciences (SAMS) that would make assisted suicide a normal part of doctors' medical responsibilities. Under the new guidelines, “assisted suicide [by physicians] is justifiable in the case of patients capable of judgement, if the symptoms of disease or functional impairments are causing them intolerable suffering, and other options have proved ineffective or been rejected as unacceptable.” The new guidelines are part of a set entitled Management of Dying and Death that cover topics such as advance care planning and care and support for relatives. <https://goo.gl/AbgHVc>

1. ‘Management of Dying and Death,’ Swiss Academy of Medical Sciences, June 2018. **Download/view at:** <https://goo.gl/BhBpHu>

Journal Watch

Open access journals and predatory publishing in palliative care

MEDICINA PALIATIVA, 2018;25(3):184-190. The authors found 32 open access journals in the field of palliative care (PC) with full or partial open access option; three of them were not active. The median original publication fee was 1,389€. Globally, three types of journal could be distinguished: 9 journals of recognized publishers, indexed and even with impact factor, that allow the possibility of publishing with open access; 7 open access scholarly journals, some indexed and with impact factor, that only publish open access, and 16 suspected predatory journals. The authors found an association between the presence of the journal on Beall's list and some suspicion criteria for predatory publishing such as: absence of impact factor or PubMed indexation; no Open Access Scholarly Publishers Association registration; e-mails requesting works; option of payment per time period; and flexibility in payment according to type of article. **Abstract:** <https://goo.gl/7eimmH>

N.B. Spanish language article.

Noted in Media Watch 19 March 2018 (#555, p.15):

- *UNIVERSITY AFFAIRS* | Online – 5 March 2018 – ‘**Poor quality, predatory conferences prey on academics.**’ Many publishers of deceptive or poor-quality academic journals have created a big side-line business organizing equally questionable academic conferences. Yet some professors don't seem to be getting the message to stay away. McGill University professor Eduardo Franco discovered last year, to his dismay, that OMICS International, one of these publishers, listed 220 McGill professors whom the company claimed had served as “editors, contributors and speakers” for OMICS journals and conferences. **Full text:** <https://goo.gl/h5G9ed>

N.B. The OMICS publications include the *Journal of Palliative Care & Medicine*: <http://goo.gl/ieTbLZ>. In November 2017, a U.S. federal court granted a preliminary injunction against OMICS requested by the Federal Trade Commission “temporarily halting the deceptive practices” of the publisher.

Media Watch: Editorial Practice

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

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5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Cont.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/T2tCWF>

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

PALLIATIVE CARE NETWORK: <https://goo.gl/XWZw5W>

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

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at <https://goo.gl/6vdk9v>]

Asia

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

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?']

Cont.

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>

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[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/L7D2hw>

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

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



Closing the Gap Between Knowledge & Technology

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