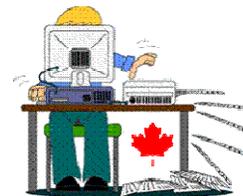


Media Watch...

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.

13 November 2017 Edition | Issue #538



Compilation of Media Watch 2008-2017 ©

Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to [Specialist Publications](#) and “A strange kind of balance”: Inpatient hospice volunteers’ views on role preparation and training’ (p.16), in *Progress in Palliative Care*.

Canada

Court cases raise questions about legal definition of death

ONTARIO | *The Toronto Sun* – 9 November 2017 – Two Ontario court cases involving people deemed brain dead are raising questions about whether what constitutes death should be clearly spelled out under Canadian laws. The issue is at the crux of separate legal battles to keep 27-year-old Taquisha McKitty of Brampton and 25-year-old Shalom Ouanounou of Toronto on life support.^{1,2} Both cases involve religious objections to the concept of brain death. The lawyer representing both families argues the absence of a legal definition of death creates somewhat of a grey area, particularly when it comes to issues such as religious accommodation. Only Manitoba has legislation that explicitly defines death, which it says takes place “at the time at which irreversible cessation of all that person’s brain function occurs.” Most other provinces and territories allude to the matter in legislation surrounding organ donation, typically by saying death will be determined according to accepted medical practices, without specifying what those are. But some legal and medical experts say enshrining the definition of death in law wouldn’t change much, nor would it necessarily prevent future court challenges. And imposing a rigid definition could create issues down the road, they say. <https://goo.gl/D3yntd>

Specialist Publications

‘Appeal to physicians – opioids have their place. Let’s avoid an unintended tragedy’ (p.9), in *Canadian Medical Association Journal*.

‘Just get on with improving palliative care, plead experts’ (p.10), in *Canadian Medical Association Journal*.

‘(Mis)understandings and uses of “culture” in bioethics deliberations over parental refusal of treatment: Children with cancer’ (p.8), in *Clinical Ethics*.

‘Moving from place to place in the last year of life: A qualitative study identifying care setting transition issues and solutions in Ontario’ (p.12), in *Health & Social Care in the Community*.

‘The final 30 days of life: A study of patients with gastrointestinal cancer in Ontario, Canada’ (p.14), in *Journal of Palliative Care*.

‘Euthanasia requests in a Canadian psychiatric emergency room: Part 1 of the McGill University euthanasia in psychiatry case series’ (p.16), in *International Journal of Law & Psychiatry*.

Cont.

1. 'More time for Brampton family fighting to keep woman on life support,' *The Brampton Guardian*, 7 November 2017. <https://goo.gl/ai9uAd>
2. 'Orthodox Jewish family wants brain dead son's death certificate rescinded because faith won't accept he's deceased,' *The National Post*, 1 November 2017. [Noted in the 6 November 2017 issue of Media Watch (#537, p.1)] <https://goo.gl/ksLQv>

New plan will see Ontario government employees deliver home care

ONTARIO | CBC News (Toronto) – 6 November 2017 – The Wynne government is getting into the business of providing home care directly, quietly creating a new provincial agency that could eventually serve hundreds of thousands of patients in Ontario, CBC News has learned. The move would mean personal support workers (PSWs) become provincial employees. It also has the potential to take a significant portion of the \$2.5 billion in annual publicly-funded home care away from the for-profit and not-for-profit agencies currently providing it. The government says creating the agency would give home-care clients more choice in selecting a PSW and more control in determining their care schedule. The move to increase public delivery of publicly-funded health services will likely be welcomed by some advocates who've been critical of Ontario relying on private-sector agencies to provide home care. <https://goo.gl/BJL3jT>

Noted in Media Watch 1 May 2017 (#510, p.1):

- ONTARIO | CBC News (Toronto) – 25 April 2017 – '**Ontario set to begin shifting home care responsibilities.**' Ontario begins dissolving its 14 community care access centres (CCACs) ... but, critics insist the move won't cut red tape, free up money or improve home care for patients. Every year more than 700,000 people in Ontario count on the personal support workers, nurses and therapists who are funded by CCACs. But the CCACs have been the subject of damning audits, and last December the government passed its Patients First Act,¹ which handed the responsibility of home care to the local health integration networks in each region. The Ministry of Health & Long Term Care claims the merger will streamline administration of the health care system and lead to better home care. But home care advocates aren't convinced. <https://goo.gl/bvwyYq>

1. 'Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario,' Ministry of Health & Long Term Care, 17 December 2015. **Download/view at:** <http://goo.gl/XVoGO3>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | CBC News (Winnipeg) – 7 November 2017 – '**Doctors, advocacy groups address proposed law protecting those who object to assisted dying.**' The Medical Assistance in Dying (Protection for Health professionals and Others) Act, which would protect medical professionals from disciplinary action for refusing to provide or aid in providing medical assistance in dying services, went to hearings before a standing committee. The bill was introduced to the legislature in May and underwent a second reading last week. The committee process allows the public to voice concerns or show support for the proposed bill, and ask for other considerations to be made. <https://goo.gl/7vMogH>

Specialist Publications

'**The evolving role of the personal support worker in home care in Ontario, Canada**' (p.12), in *Health & Social Care in the Community*.

Services at home at end of life in Ontario

Access to home palliative care in the province is addressed in 'Palliative Care at the End of Life' – 'Services at home at end of life' (pp.11-21) – published by Health Quality Ontario.¹

1. 'Palliative Care at the End of Life,' Health Quality Ontario, June 2016. [Noted in the 4 July 2016 issue of Media Watch (#469, p.2)] **Download/view at:** <http://goo.gl/GW0Xh9>

U.S.A.

Let's rank hospitals by the quality of their end-of-life care

MASSACHUSETTS | STAT (Boston) – 9 November 2017 – Now death has effectively turned into dying, a phase of our lives rather than a momentary occurrence, there is increased interest in helping people achieve a “good death.” Many people want to die at home.¹ That preference is at odds with reality – most Americans pass away in health care facilities.² Research I published recently with two colleagues showed that only one-third of U.S. residents with heart disease die at home.³ Given that many people die in hospitals, it makes sense to rank hospitals on how well they manage patients' deaths. Two questions lie at the heart of a ranking for end-of-life care (EoLC): What, exactly, constitutes a good death? And can those elements be quantified? We think we know what constitutes good medical care, and that is reflected in the quality measures we use to reward and penalize hospitals. Good medical care is affordable, accessible, safe, and appropriate, each of which can be quantified by well-developed metrics. These have gained traction for assessing general medical care. Quality improvement at the end of life has attracted less attention. Few researchers have tried to enumerate the components of a good death. One who has is Dr. Arif Kamal, an oncologist and palliative care physician at Duke University. He has worked with national organizations to define quality metrics for EoLC.⁴ Many people associate a good death with natural death, another ill-defined concept. The dearth of information on EoLC means that even as we are

getting better at figuring out how good hospitals are at helping their patients stay alive and live, we have no way of knowing how good they are at helping their patients when they are dying. <https://goo.gl/FZQJdy>

Specialist Publications

'Reasons to amplify the role of parental permission in pediatric treatment' (p.8), in *American Journal of Bioethics*.

'Facilitators and barriers for advance care planning among ethnic and racial minorities in the U.S.: A systematic review of the current literature' (p.13), in *Journal of Immigrant & Minority Health*.

'Survey on neonatal end-of-life comfort care guidelines across America' (p.14), in *Journal of Pain & Symptom Management*.

'Gender and geographic differences in Medicare service utilization during the last six months of life' (p.15), in *Journal of Women & Aging*.

'Barriers to physician aid in dying for people with disabilities' (p.17), in *Laws*.

'When dying becomes unaffordable' (p.17), in *MedScape*.

1. 'Place of care in advanced cancer: A qualitative systematic literature review of patient preferences,' *Journal of Palliative Medicine*, 2005,3(3):287-300. **Abstract:** <https://goo.gl/TdZFHj>
2. 'Epidemiology and patterns of care at the end of life: Rising complexity, shifts in care patterns and sites of death,' *Health Affairs*, 2017;36(7):1175-1183. Included in a special issue on end-of-life care. [Noted in the 10 July 2017 issue of Media Watch (#520, p.10)]. **Journal contents page:** <https://goo.gl/jebK3j>
3. 'How medicine has changed the end of life for patients with cardiovascular disease,' *Journal of the American College of Cardiology*, 2017;70(10):1276-1289. [Noted in the 4 September 2017 issue of Media Watch (#528, p.9)] **Abstract:** <https://goo.gl/aagwMe>
4. 'The quality imperative for palliative care,' *Journal of Pain & Symptom Management*, 2015;49(2):243-253 (first published online 21 July 2014). [Noted in the 28 July 2014 issue of Media Watch (#368, p.8)] **Abstract:** <https://goo.gl/P5a3iY>

A world of hurt: The international lack of palliative care

MINNESOTA | RAC Monitor (St. Paul) – 9 November 2017 – *The Lancet* [recently] published its Commission's report on the international lack of palliative care and pain relief.¹ It is a 64-page tale documenting the woeful state of unrelieved global suffering. Everywhere on earth ... "people live and die with little or no PC or pain relief." The Commission describes an "access abyss" in which the poor live and die in extreme suffering without hope of receiving pain-relieving medications. They describe the fact that most of humanity lives in a world of hurt. The article documents the astounding maldistribution of pain relievers known as "morphine equivalent opioids" (MEOs). It is not only the poor countries' poor who experience "serious health-related suffering" (SHS) needlessly, but also the rich countries' poor – and, frequently, the rich countries' rich. In poorer nations, this vulnerable group lacks the access to "inexpensive, essential, and effective intervention" to relieve their physical torment. In our country, there are frequent reports that despite the 55,000 mg of MEOs available per patient, many patients live with unrelieved SHS. In the authors' opinion, this is "a medical, public health, and moral failing" by the global health community, which includes our part of the globe – the U.S. America's patients enduring SHS are also in this world of hurt. <https://goo.gl/nRhkWo>

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

Hospice workers who care for the dying don't plan ahead themselves

FLORIDA | *Kaiser Health News* – 7 November 2017 – Hospice workers may witness terminal illness and death almost daily, but that doesn't mean they've documented their own end-of-life wishes, a new report finds.¹ A survey of nearly 900 health care workers at a non-profit Florida hospice found that fewer than half – just 44% – had completed advance directives. Of the rest, 52% said they had not filled out the forms that specify choices about medical care. Nearly 4% said they weren't sure if they had or not. Equally surprising, about 10% of hospice workers without directives said they didn't know where to obtain the forms – which are widely available online. Another nearly 6% said cost was a barrier, even though the documents can be completed for free, without an attorney's help. <https://goo.gl/XsSFF1>

1. 'Advance directives in hospice healthcare providers: A clinical challenge,' *American Journal of Medicine*, 2017;130(11):e487-e489 (first published online 7 August 2017). [Noted in the 14 August 2017 issue of Media Watch (#525, p.7)] **Full text:** <https://goo.gl/BWoQvQ>

For patients with heart failure, little guidance as death nears

THE NEW YORK TIMES | Online – 6 November 2017 – The number of Americans with heart failure increased to 6.5 million in 2011-2014 from 5.7 million in 2009-2012, according to the American Heart Association. More than 10% of those over age 80 have heart failure, and more patients are living longer with advanced disease. Even as the death rate from heart attacks is falling, the figure for heart failure is rising. Yet there are no widely accepted guidelines for dealing with these patients as they near death. Cancer specialists regularly move their patients to hospice at the end of life (EoL), for instance, but few cardiologists even think of it. Heart patients account for just 15% of hospice deaths, while cancer patients make up half, according to a recent study.¹ That paper ... reviewed a number of ways in which heart patients are let down at the EoL. Implanted defibrillators often remain activated until the very end, for example, even for those in hospice. A fifth of heart patients with defibrillators get shocked by them in the last few weeks of life, and 8% get shocked minutes before dying. Most patients are never told that they can ask that the defibrillators be turned off. <https://goo.gl/p3dJsB>

1. 'How medicine has changed the end of life for patients with cardiovascular disease,' *Journal of the American College of Cardiology*, 2017;70(10):1276-1289. [Noted in the 4 September 2017 issue of Media Watch (#528, p.9)] **Abstract:** <https://goo.gl/C1Fw1N>

Noted in Media Watch 16 October 2017 (#534, p.10):

- *JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY*, 2017;70(15):1919-1930. '**Palliative care in heart failure: Rationale, evidence, and future priorities.**' While the evidence base for palliative care (PC) in heart failure (HF) is promising, it is still in its infancy and requires additional high-quality, methodologically sound studies to clearly elucidate the role of PC for patients and families living with the burdens of HF. Yet, an increase in attention to primary PC ... provided by primary care and cardiology clinicians, may be a vehicle to address unmet palliative needs earlier and throughout the illness course. **Abstract:** <https://goo.gl/rqfdL4>

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 the 18 September 2017 issue of Media Watch (#530, p.2)] **Abstract:** <https://goo.gl/2u9mE2>

N.B. Additional articles on palliative and end-of-life care for people living with heart failure are noted in the 28 August 2017 issue of Media Watch (#526, pp.11-12).

What it's like to learn you're going to die

THE ATLANTIC | Online – 2 November 2017 – Nessa Coyle calls it “the existential slap” – that moment when a dying person first comprehends, on a gut level, that death is close. For many, the realization comes suddenly: “The usual habit of allowing thoughts of death to remain in the background is now impossible,” Coyle, a nurse and palliative care pioneer, has written. “Death can no longer be denied.” For many patients with terminal diseases, Coyle has observed, this awareness precipitates a personal crisis. Researchers have given it other names: the crisis of knowledge of death; an existential turning point, or existential plight; ego chill. It usually happens as it did with my mother, close to when doctors break the news. Doctors focus on events in the body: You have an incurable disease; your heart has weakened; your lungs are giving out. But the immediate effect is psychological. Gary Rodin, a palliative care specialist who was trained in both internal medicine and psychiatry, calls this the “first trauma”: the emotional and social effects of the disease. <https://goo.gl/1EXnvw>



[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

New Warkworth Wellsford hospice centre a New Zealand first in design

NEW ZEALAND | Voxy.com.nz (Wellington) – 9 November 2017 – A new Warkworth Wellsford Hospice centre, with architecture influenced by ‘The Architecture of Hope’ from Maggie’s Centres abroad and offering wraparound care within, will be the first of its kind in New Zealand. The new Hospice, Tui House, offers a fresh approach in both architecture and health, hosting private and semi-private spaces with most rooms connecting to the outdoors. A distinguishing feature of the Warkworth building is that it is based on the concept of a barn to suit the largely rural area it serves and to provide a hopeful, open energy space which is homely, welcoming and familiar. <https://goo.gl/TEwNPC>

Noted in Media Watch 21 November 2016 (#488, p.7):

- *CHANGE OVER TIME*, 2016;6(2):248-263. ‘**Home and/or hospital: The architectures of end-of-life care.**’ The architects of hospices, palliative care facilities, and the U.K.-based Maggie’s Centres strive to make their buildings look like houses to express a collective environment of caring, emphasizing quality-of-life issues over medical efficiency. This reflects larger changes in the design of therapeutic landscapes since 1980, which endeavor to normalize illness and death by engaging architecture as a tool of distraction. **Abstract:** <https://goo.gl/1bFLGg>

The last thing you’ll ever hear: What is the world’s best deathbed music?

U.K. (Scotland) | *The Guardian* (Glasgow) – 9 November 2017 – Why is there so little music for the dying? Maybe we’re shy of these fragile moments, feeling they’re too intimate to intrude upon with any extraneous sounds. But a deathbed doesn’t need to be hushed. Matthew Lenton is the director of Vanishing Point, the Glasgow theatre company whose new co-production with Scottish Ensemble explores the role of music in end-of-life care. According to one U.S. report, music can “decrease depressive symptoms and social isolation, increase communication and self-expression, stimulate reminiscence and life review, and enhance relaxation.”¹ The Scottish Ensemble has been doing its own investigations. At a Maggie’s Centre in Dundee, its string players asked patients what music helped them feel the most mindful, the most calm and present in the moment. The most popular choice, though, was the light-filled music of Estonian Arvo Pärt – ‘Tabula Rasa.’² <https://goo.gl/w49MY3>

1. ‘The use of music in facilitating emotional expression in the terminally ill,’ *American Journal of Hospice & Palliative Medicine*, 2004;21(4):255-260. **Abstract:** <https://goo.gl/SPoifW>
2. Embedded in *The Guardian* article is a link to a recording of ‘Tabula Rasa.’ AIDS activist Patrick Giles (1957-2002), in a 1999 article for *Salon*, reported that when he played this piece of music “for those facing the final onslaught of the disease” they developed a peculiar, almost desperate attachment to it. **Full text of *Salon* article:** <https://goo.gl/QFypvb>



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.

Specialist Publications

‘The “Charter of Rights for Family Caregivers.” The role and importance of the caregiver: An Italian proposal’ (p.11), in *ESMD Open*.

‘Palliative care and hospice: A paradigm for end-of-life care in developing nations’ (p.13), in *Journal of Advances in Internal Medicine*.

‘What can we learn from simulation-based training to improve skills for end-of-life care? Insights from a national project in Israel’ (p.13), in *Israel Journal of Health Policy Research*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BELGIUM | *The Brussels Times* – 6 November 2017 – ‘**Euthanasia and palliative care go hand in hand.**’ Seven out of ten people who were euthanised in 2013 also received support from a palliative care (PC) team. This figure is higher than those who, in the same period, died not through euthanasia but in fact naturally. In the latter group, only 42.5% of those who died received some form of PC. The team of end-of-life care researchers from the Flemish-speaking Free University of Brussels and the University of Ghent analysed a sample of 3,751 deaths in 2013. It emerges, from the study, that the PC teams were involved in the decision-taking and/or the execution relating to the death for nearly six out of ten people who opted for euthanasia. <https://goo.gl/P5M58m>
- AUSTRALIA (Victoria) | *The Conversation* (Melbourne) – 5 November 2017 – ‘**The fear that dare not speak its name: How language plays a role in the assisted dying debate.**’ Three terms loomed large a few weeks ago in the debate in parliament: “euthanasia”, “assisted dying” and “assisted suicide.” Those who supported the Voluntary Assisted Dying Bill tended to use the phrase “assisted dying” throughout the debate. A preliminary token count (factoring out references to the name of the bill) shows 678 references to “assisted dying” from 17-19 October. The lion’s share of these were made by the bill’s proponents. Conversely, those who opposed the bill favoured the terms “euthanasia” and “assisted suicide.” There were 264 references to “euthanasia” and 205 to “assisted suicide” across the three days. These terms were most often used by the bill’s opponents. In fact, the bill’s opponents took issue with its euphemistic tone. Deputy Premier James Merlino argued in the debate that “language is important” and pointed out the reticence of the bill’s proponents to use “confronting words” like “euthanasia” or “suicide.” <https://goo.gl/LeZDFE>

Related

- AUSTRALIA (Victoria) | Special Broadcasting Service (Melbourne) – 10 November 2017 – ‘**Poll shows assisted dying support high.**’ Eighty-seven per cent of respondents said they support voluntary euthanasia, up 18% since the poll was done in 1996... When the research agency first asked people the question in 1962, the population was divided, with 47% favouring allowing a doctor to give a lethal dose, versus 39% against and 14% undecided. <https://goo.gl/zHmPEF>

Specialist Publications

The views of adults with neurodegenerative diseases on end-of-life care: A metasynthesis

AGING & MENTAL HEALTH | Online – 6 November 2017 – Improving end-of-life care (EoLC) for people with neurodegenerative diseases is seen as a clinical priority. In order to do this, it is important to take into account the views expressed by people with these conditions on their experiences of this care. Four themes were identified; 1) Importance of autonomy and control; 2) Informed decision-making and the role of healthcare professionals; 3) Contextual factors in decision-making; and, 4) The pitfalls of care. Participants’ views were framed by the context of their lives and experience of their illness and these shaped their engagement with EoLC. Care needs to be individualised and needs-based, implementing palliative care in a timely way to prevent crises and loss of autonomy. **Abstract:** <https://goo.gl/UjtXjy>

N.B. Additional articles on palliative and end-of-life care for people – both patients and family caregivers – living with a neurodegenerative disease are noted in the 16 October 2017 issue of *Media Watch* (#534, p.10)]

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Reasons to amplify the role of parental permission in pediatric treatment

AMERICAN JOURNAL OF BIOETHICS, 2017; 17(11):6-14. Two new documents from the Committee on Bioethics of the American Academy of Pediatrics (AAP) expand the terrain for parental decision making, suggesting that pediatricians may override only those parental requests that cross a harm threshold. These new documents introduce a broader set of considerations in favor of parental authority in pediatric care than previous AAP documents have embraced. While the authors find this to be a positive move, they argue that the 2016 AAP positions actually understate the importance of informed and voluntary parental involvement in pediatric decision making. This article provides a more expansive account of the value of parental permission. In particular, the authors suggest that an expansive role for parental permission may 1) Reveal facts and values relevant to their child's treatment; 2) Encourage resistance to sub-optimal default practices; 3) Improve adherence to treatment; 4) Nurture children's autonomy; and, 5) promote the interests of other family members. **Abstract:** <https://goo.gl/wVpfyM>

When doctors and parents don't agree: The story of Charlie Gard

JOURNAL OF BIOETHICAL INQUIRY | Online – 6 November 2017 – This discussion follows a series of high profile cases involving a terminally ill child, Charlie Gard. These cases are significant as they trace the complexities that arise when parents and medical teams do not agree as well as addressing the question of whether there is a right to access experimental treatment. At its heart it is a story of human suffering, hope (and despair) and how a court can manage situations of unreconcilable differences of opinion regarding what is in the best interests of a child. The legal case involving Charlie Gard, Great Ormond Street Hospital and Charlie's parents Constance Yates and Chris Gard was heard at all levels of the U.K. courts before progressing to the European Court of Human Rights and finally returning to the Family Division of the High Court. This series of cases serve as a cautionary tale, sometimes those closest to a sick person are not in the best position to make decisions, tragedy and grief, combined with offers of hope can cloud judgement. **Full text:** <https://goo.gl/Mu5jw4>

N.B. Selected articles/reports on the Charlie Gard case are noted in the 25 September 2017 issue of Media Watch (#531, p.11).

N.B. This issue of the *American Journal of Bioethics* focuses on the medical decision-making process in pediatrics. **Journal contents page:** <https://goo.gl/yQE2Lk>

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 9 November 2017 – ‘**Unexpected survivors: Children with life-limiting conditions of uncertain prognosis.**’ “Unexpected survivors,” defined as children who survived despite a prognosis of imminent death or significantly longer than prognosticated by health-care providers, were identified from among 349 children enrolled in a pediatric palliative care program [in a tertiary-care children's hospital in North Carolina]. Clinicians should be aware of the possibility of prognostic inaccuracy, able to communicate prognostic uncertainty to parents, and engage supportive services when prognosticating poor survival. **Abstract:** <https://goo.gl/xi3kpr>
- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 10 November 2017 – ‘**Individualised advance care planning in children with life-limiting conditions.**’ In 2013, the Pediatric Association of The Netherlands launched an evidence-based guideline, ‘Palliative Care for Children.’ To promote implementation in daily practice and thereby improve quality of paediatric palliative care, the authors developed a functional individualised paediatric palliative care plan (IPPCP) that covers physical, psychological, spiritual and social functioning, with emphasis on the guideline's recommendations, advance care planning and patients' and parents' preferences and desires. **Abstract:** <https://goo.gl/Bwx7Qi>
- *CLINICAL ETHICS* | Online – 6 November 2017 – ‘**(Mis)understandings and uses of “culture” in bioethics deliberations over parental refusal of treatment: Children with cancer.**’ Recent cases in Canada where courts have declined applications by clinicians for court orders to overrule parental refusal of treatment highlight the dispute in this area. This study analyses the 16 cases of a larger group of 24 cases that were selected by a literature review where cultural or religious beliefs or ethnic identity was described as important reasons behind the refusal. The most significant finding was that nearly all of the cases cited unacceptable side effects as the main reason for declining treatment. **Abstract:** <https://goo.gl/VjaTRQ>

Measuring processes of care in palliative surgery: A novel approach using natural language processing

ANNALS OF SURGERY | Online – 3 November 2017 – Palliative surgical (PS) procedures are often performed for patients with limited survival. Quality measures for processes of care at the end of life (EoL) are appropriate in PS, but have not been applied in this patient population. The authors propose four quality measures for EoL care in a PS, and then demonstrate the utility of natural language processing for implementing these measures. **Abstract:** <https://goo.gl/BzzKHc>

N.B. Click on pdf icon to access full text.

Noted in Media Watch 3 April 2017 (#506, p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 24 March 2017 – ‘**Palliative care in surgery: Defining the research priorities.**’ The objective of this article is to describe the existing science of palliative care in surgery within three priority areas and expose specific gaps within the field. The authors propose a research agenda to address these gaps and provide a road map for future investigation. **Abstract:** <https://goo.gl/RGRopi>

Appeal to physicians – opioids have their place. Let’s avoid an unintended tragedy

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 6 November 2017 – A well-known tragedy has occurred with respect to opioids – the crisis of overdose deaths from opioids that were obtained from various legitimate and illegitimate sources. This has necessitated urgent government and public action. A second, preventable tragedy is beginning to occur as an unintended consequence of the first. The stigma around opioid use has become so strong that patients, families, and health care practitioners are afraid to receive or prescribe them, leaving patients to suffer unnecessarily. We are referring specifically to palliative care (PC), a context where opioids are sometimes the most appropriate choice for pain and dyspnea management. This is clearly outlined in the Society’s ‘Position Statement on Access to Opioids for Patients Requiring Palliative Care.’¹ The ‘Canadian Guideline for Opioids for Chronic Non-Cancer Pain’ made recommendations for opioid prescribing in the chronic non-cancer pain population based on a systematic review of the literature specific to that population.² The guideline clearly states that exceptions are appropriate under some circumstances, including PC and cancer pain. Unfortunately, many physicians have misunderstood the guideline to apply to all patients, including those appropriately receiving a palliative approach to care. Many physicians have expressed reluctance to prescribe opioids for such patients, even those approaching the end of their lives. Some physicians have stopped ordering opioids altogether. Unaddressed and unnecessary suffering is the result. The Society believes patients with palliative needs who require appropriately prescribed opioids to manage symptoms should not have opioids withheld in an attempt to adhere to guidelines that are meant for a different patient population, or due to fear of regulatory oversight. **Full text:** <https://goo.gl/VzahC4>



1. ‘Position Statement on Access to Opioids for Patients Requiring Palliative Care,’ Canadian Society of Palliative Care Physicians, August 2016. [Noted in the 15 August 2016 issue of Media Watch (#475, p.1)] **Download/view at:** <https://goo.gl/GZP5i6>
2. ‘The 2017 Canadian Guideline for Opioids for Chronic Non-Cancer Pain,’ College of Family Physicians of Canada, May 2017. **Download/view at:** <https://goo.gl/yr3Pfq>

Noted in Media Watch 5 June 2017 (#515, p.1):

- CANADA (Ontario) | *The Toronto Star* – 1 June 2017 – ‘**How a 1980 letter on drug addiction fuelled the opioid epidemic.**’ Nearly 40 years ago, a respected doctor wrote a letter to the *New England Journal of Medicine* with some very good news: out of nearly 40,000 patients given powerful pain drugs in a Boston hospital, only four addictions were documented.¹ Doctors had been wary of opioids, fearing

Cont.

patients would get hooked. Reassured by the letter, which called this “rare” in those with no history of addiction, they pulled out their prescription pads and spread the good news in their own published reports. And that is how a one-paragraph letter with no supporting information helped seed a nationwide epidemic of misuse of drugs such as Vicodin and OxyContin by convincing doctors that opioids were safer than we now know them to be. <https://goo.gl/u1ccqk>

1. ‘A 1980 letter on the risk of opioid addiction,’ *New England Journal of Medicine*, 2017;376(22):2194-2195. **Full text:** <https://goo.gl/p9oIC7>

Noted in Media Watch 29 February 2016 (#451, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 February 2016 – ‘**The pendulum swings for opioid prescribing.**’ For most of the 20th century, a common belief among the public, including physicians, is that an opioid like morphine, even if prescribed by a physician for a medical indication, causes addiction. The consequence was extraordinary and unnecessary suffering after surgical operations, trauma, and cancer. The 1990s and 2000s saw an increase in the willingness of physicians to prescribe opioids because of the correction of this fundamental misunderstanding. Although we learned that pain is complex, and multifactorial, and that opioids are good for some kinds of pain, there are other kinds of pain where it doesn’t work at all. But nuance doesn’t make for good marketing, and opioids as all-around safe analgesics for everything that hurts made for promiscuous prescribing. **Abstract:** <http://goo.gl/rDY6wn>

Palliative care in Canada

Just get on with improving palliative care, plead experts

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2017;189(44):e1376. Canada should follow through on existing plans for improving palliative care (PC) instead of wasting time developing new definitions and frameworks, experts told the Standing Senate Committee on Social Affairs, Science & Technology. The Senate is studying Bill C-277,¹ which would see the government develop a framework to promote access to PC and consider re-establishing a PC secretariat at Health Canada. The bill won unanimous support in the House of Commons. But, according to Dr. José Pereira, scientific officer for the advocacy group Pallium Canada, there’s no need to “reinvent frameworks, as they are already in place.” Resurrecting Canada’s secretariat on end-of-life care, however, would provide “focus, attention and much needed visibility,” he said. The federal government previously funded the development of a 2013 framework by the Canadian Hospice Palliative Care Association (CHPCA).² Provinces have endorsed and are already using that plan, CHPCA Executive Director Sharon Baxter told senators. “They just need the initiative funding to

get it to actually happen.” Senators also questioned why it’s necessary for the federal government to redefine PC when there’s already consensus among health professionals. The bill’s sponsor, Conservative MP Marilyn Glau, agreed that the government “doesn’t need to begin with a blank page,” and the bill directs them to reference previous frameworks. The intent of the bill is to set “minimum standards of what will be covered everywhere,” she said. **Full text:** <https://goo.gl/C6GdT3>

Improving access to palliative care in Canada well studied

Nine key studies on the need to improve access to palliative care in Canada, published between 1995 and 2014, are listed in the 22 December 2014 issue of *Media Watch* (#389, p.4). The Canadian Cancer Society published ‘Right to Care: Palliative care for all Canadians,’ in December 2015. [Noted in the 18 January 2016 issue of the weekly report (#445, p.1)] **BRA**

1. ‘An Act Providing for the Development of a Framework on Palliative Care in Canada,’ Private Member’s Bill. **Download/view at:** <https://goo.gl/MtPZiU>
2. ‘The Way Forward National Framework: A roadmap for an integrated palliative approach to care,’ Canadian Hospice Palliative Care Association. **Download/view final version published March 2015 at:** <https://goo.gl/N4Rypr>

Cont.

N.B. See 'A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice,' Canadian Hospice Palliative Care Association. **Download/view revised and condensed edition published September 2013 at:** <https://goo.gl/4NdCv8>

Related

- *ACADEMIC MEDICINE* | Online – 7 November 2017 – **'You're not trying to save somebody from death': Learning as "becoming" in palliative care.'** This study demonstrates that memorable learning in palliative care (PC) is a complex interplay of individual and workplace experience that is not adequately explained by a conceptualization of learning as "acquisition" or "participation." Learning as a process of "becoming" that considers and supports individuals, their entanglement in clinical workplaces, and the development of professional identity is a more apt description to appreciate PC learning. The practice of PC presented post-graduate learners in this study with novel ways of being a physician and engaging with patients, families, and interprofessional teams. Evidence from this study supports the creation of meaningful clinical experiences and reflective spaces for dialogue to support professional identity formation. **Abstract:** <https://goo.gl/JjJ7m1>

N.B. Click on pdf icon to access full text.

The "Charter of Rights for Family Caregivers." The role and importance of the caregiver: An Italian proposal

ESMD OPEN (European Society for Medical Oncology) | Online – 4 November – Cancer diagnosis not only shakes the lives of those who are affected, but also has impacts on the entire family system, which is involved as if it were itself an organism affected by cancer. The oncological illness may cause a breakdown of the existing balance in the family system and demands a progressive degree of mutual adaptation to family members. The 'VoiNoi' Listening Centre of the Campus Bio-Medico University Hospital in Rome has been close to caregivers for several years, to support them in the difficult task of providing assistance through individual or group psychological support therapy and health education. The 'Charter of Rights for Family Caregivers' stems from the experience gained over the years, with the aim of protecting, supporting and strengthening the role and the assistance activity that families carry out in support of their loved ones under conditions of fragility. **Full text:** <https://goo.gl/Yn14sU>

N.B. 'VoiNoi' Listening Centre, Campus Bio-Medico University Hospital, website: <https://goo.gl/y2xTdZ>

How the rise of medical technology is worsening death

HEALTH AFFAIRS | Online – 6 November 2017 – Medical technology can indeed be miraculous. It has saved countless lives that in previous times would have been lost. But there can be substantial costs, both human and financial. Many patients die protracted deaths on mechanical ventilators – deaths which, based on data about preferences, many would not have chosen had there been adequate communication. Even a treatment with a powerful record and clear physiologic indication might, in some, cause profound suffering. Patients need to understand that potential at the outset of their treatment and remain in clear communication with their physicians as their trajectories unfold. Physicians, as stewards of these technologies, have a responsibility to direct the use of these technologies toward patients who are most likely to benefit, instead of viewing these treatments as a default for all patients. And once they have attached their patients to these technologies, physicians must engage in ongoing dialog with the patient or family to ensure that the medical plan remains in alignment with the patient's preferences, which may change as the prognosis becomes clearer. As new life-support technologies such as extracorporeal membrane oxygenation are used more widely, more patients will be left stranded on the "bridge to nowhere." As a society, we must look carefully at our U.S. tendency to celebrate technology and to assume that "doing something" implies that we care. **Full text:** <https://goo.gl/HAH11R>

The evolving role of the personal support worker in home care in Ontario, Canada

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 8 November 2017 – [A review of home-care service user charts] indicate that normally personal support workers (PSWs) provide personal and supportive care commensurate with their training. However, in approximately one quarter of care plans reviewed, PSWs also completed more complex care activities transferred to them by regulated health professionals (RHPs). Although there is potential for the expansion of home-care services through increased utilisation of PSWs, healthcare leadership must ensure that the right provider is being utilised at the right time and in the right place to ensure safe and effective quality care. Several actions are recommended: PSW core competencies be clearly articulated, processes used to transfer care activities from RHPs to PSWs be standardised and a team-based approach to the delivery of home-care services be considered. Utilisation of a team-based model can help establish positive relationships among home-care providers, provide increased support for PSWs, allow for easier scheduling of initial training and ensure regular re-assessments of PSW competence among PSWs providing added skills. **Abstract:** <https://goo.gl/hhUVbq>

Moving from place to place in the last year of life: A qualitative study identifying care setting transition issues and solutions in Ontario, Canada

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 6 November 2017 – Moving from one care setting to another is common as death nears. Many concerns exist over these end-of-life care setting transitions, including low-quality moves as mistakes and other mishaps can occur. Delayed or denied moves are also problematic, such as a move out of hospital for dying inpatients who want to spend their last hours or days at home. The aim of the study was to identify current issues or problems with care setting transitions during the last year of life as well as potential or actual solutions for these problems. A grounded theory analysis approach was used based on interviews with 38 key informants who represent a wide range of healthcare providers, healthcare managers, government representatives, lawyers, healthcare recipients and their family/friends across Ontario in 2016. Three interrelated themes were revealed: 1) Communication complexities; 2) Care planning and coordination gaps; and, 3) Health system reform needs. Six solutions were highlighted, with these designed to prevent care setting transition issues and monitor care setting transitions for continued improvements. **Abstract:** <https://goo.gl/o3gU7H>

N.B. This article is based on a study undertaken by the authors for the Law Commission of Ontario, 'Improving Care Setting Transitions in the Last Year of Life.' The study, together with others published as part of a Commission's initiative, 'Improving the Last Stages of Life,' can be **downloaded/viewed at:** <https://goo.gl/vqFDKY>

Physician guide to home hospice visits

HOME HEALTH CARE MANAGEMENT & PRACTICE | Online – 3 November 2017 – The field of hospice and palliative medicine continues to grow, attracting recent graduates as well as more senior physicians looking for career changes. Unfortunately, there is little, if any, training in most residencies regarding the home hospice visit, and there are not enough fellowship-trained physicians to fill the available positions. A systematic review of the literature was made for the years 2000 to 2016 to identify articles which provided practical, clinical guidelines for the physician home hospice visit. No single article provided this needed information. Thus, the authors formulated these guidelines based on the literature and their experiences to aid the home hospice physician – as well as other providers who may work with the physician – to understand the physician's role in the home hospice visit. **Abstract:** <https://goo.gl/75mffl>

Noted in Media Watch 16 October 2017 (#534, p.12):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 October 2017 – '**Examining the role of primary care physicians and challenges faced when their patients transition to home hospice care.**' Studies have shown patients and caregivers desire continuity with their physicians at the end of life. However, it is unclear what roles primary care physicians (PCPs) play and what challenges they face caring for patients transitioning into home hospice care. Most PCPs [from 3 academic group practices in New York City] noted that there was a discrepancy between their actual role and ideal role when their patients transitioned to home hospice care. **Abstract:** <https://goo.gl/Z8FhyR>

Palliative care and hospice: A paradigm for end-of-life care in developing nations

JOURNAL OF ADVANCES IN INTERNAL MEDICINE, 2017;6(2):38-44. Traditionally, medical care has had two mutually exclusive goals: either to cure disease and to prolong life or to provide comfort care. Given this dichotomy, the decision to focus on reducing suffering is made usually only after life-prolonging treatment has been ineffectual and death is imminent, usually by days or hours. As a result, one of the best kept secrets in a hospital today in the U.S. is palliative and hospice care (P&HC). We estimate that of the 2.4 million Americans that die each year, about 80% end their lives in hospitals attached to the latest advances in technology; 300,000 die at home under hospice care. The reasons why more people do not receive P&HC range from the patient's fear of abandonment and the unknown, the family's denial of the inevitability of death of their loved one, and physician's denial of medicine's limitations. Unless the options of P&HC are given to patients the fears that people have of dying – fear of dying alone and fear of dying in pain – will continue to make the dying process one that lacks dignity and respect. In this review article we have reviewed the state of P&HC in the U.S. through a historical, ethical and legal perspective. **Full text:** <https://goo.gl/EhYdvy>

What can we learn from simulation-based training to improve skills for end-of-life care? Insights from a national project in Israel

ISRAEL JOURNAL OF HEALTH POLICY RESEARCH | Online – 6 November 2017 – Simulation-based training of healthcare providers is an interesting and promising method to improve quality of end-of-life care (EoLC). A series of unanticipated consequences emerged: One participant conducted a study of preparedness to end of life (EoL) at nursing homes¹ ... that was presented at the Ministry of Health and called forth a national survey of preparedness to EoL at hospitals. As a result, many institutions enacted guidelines and set up palliative care (PC) units. Participants spread by word of mouth the value of training for EoLC – resulting in demands for workshops from different disciplines: intensive care, dialysis, oncology, emergency and family medicine. Electronic media (including TV channels), newspapers and magazines covered the topic of EoLC with reference to the authors' workshops. They are invited each year to present insights from their project in lectures at dozens of national professional conferences, PC courses, research seminars, and institutional staff meetings as well as at general public audiences. While the authors cannot determine causality, coverage by media and public discourse led in recent years to the erection of several national committees for improved policy, training and regulation of EoLC. **Full text:** <https://goo.gl/L1oQMm>



1. 'Preparedness for end of life: Survey of Jerusalem district nursing homes,' *Journal of the American Geriatrics Society*, 2015;63(10):2114-2119. [Noted in the 2 November 2015 issue of Media Watch (#434, p.12)] **Abstract:** <https://goo.gl/JGeQA9>

Facilitators and barriers for advance care planning among ethnic and racial minorities in the U.S.: A systematic review of the current literature

JOURNAL OF IMMIGRANT & MINORITY HEALTH | Online – 9 November 2017 – Growing evidence suggests a low engagement in advance care planning (ACP) among ethnic minorities in the U.S. The purpose of this study was to synthesize findings from prior research about ACP among ethnic minorities. An extensive literature search was conducted using multiple electronic databases. After applying inclusion criteria, 26 studies were included. Four categories of facilitators and barriers to ACP were identified: 1) Socio-demographic factors; 2) Health status, literacy and experiences; 3) Cultural values; and, 4) Spirituality. Socio-demographic factors showed inconsistent findings regarding their association with ACP engagement. Worse health status and knowledge about ACP are common facilitators across ethnic minority groups, whereas mistrust toward the health care system was a barrier only for Blacks. Collectivistic cultural values influenced ACP engagement among Latinos and Asian Americans; however, spirituality/religion played an important role among Blacks. The implications for culturally competent approaches to promote ACP and future research directions are discussed. **Abstract:** <https://goo.gl/BtQAKQ>

Survey on neonatal end-of-life comfort care guidelines across America

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 9 November 2017 – An anonymous, electronic survey was sent to members of the American academy of Pediatrics Section on Neonatal-Perinatal Medicine. Members of the listserv include neonatologists, neonatal fellow physicians, neonatal nurses and neonatal nurse practitioners from across America (the U.S. and Canada). There were 346/3000 (11.5%) responses with wide geographic distribution and high levels of intensive care responding (46.1% level IV, 50.9% level III, 3.0% level II). Nearly half, (45.2%) reported their primary institution did not have neonatal comfort care guidelines. Of those reporting guidelines, 19.1% do not address pain symptom management. Most also do not address gastrointestinal distress, anxiety, or secretions. Thirty-nine percent of respondents stated their institution did not address physician compassion fatigue. Overall, 91.8% of respondents felt their institution would benefit from further education/training in neonatal end-of-life care. **Abstract:** <https://goo.gl/t8tb9j>

N.B. Additional articles on neonatal palliative and end-of-life care are noted in the 13 February 2017 issue of Media Watch (#499, p.15).

The final 30 days of life: A study of patients with gastrointestinal cancer in Ontario, Canada

JOURNAL OF PALLIATIVE CARE | Online – 8 November 2017 – There were 34,630 patients in the cohort [i.e., patient population studied]: 43% colon, 26% anorectal, 19% gastric, and 12% esophageal cancers. Aggressive end-of-life care (EoLC) was delivered to 65%, with a significantly decreasing trend from 64.8% in 2003 to 62.5% in 2013. Utilization of specific elements of aggressive EoLC included 8% chemotherapy, 46% emergency department (ED) visits, 49% hospital admissions, 6% ICU admissions, 45% death in hospital, and 5% death in ICU. **Abstract:** <https://goo.gl/9dVLuV>

Alcohol dependence in palliative care: A review of the current literature

JOURNAL OF PALLIATIVE CARE | Online – 30 October 2017 – Alcohol misuse affects up to 28% of palliative care (PC) inpatients. This article aims to summarize the existing literature on the care of palliative patients with alcohol dependence. Identification of alcohol-dependent patients can be improved through the use of validated tools such as ‘Cut Down, Annoyed, Guilty, Eye Opener’ (CAGE) and ‘Alcohol Use Disorders Identification Test’ (AUDIT). These patients may have specific PC needs such as increased susceptibility to terminal agitation, high prevalence of co-morbidities, and poor social support networks. Management may involve detoxification, controlled usage of alcohol, or treatment of alcohol withdrawal. Patients may derive clinical benefit when alcohol dependence is identified by health-care professionals. Routine screening should be considered. Further research is needed to directly compare treatments for alcohol dependence in PC. **Abstract:** <https://goo.gl/TV6TWa>

Noted in Media Watch 21 November 2017 (#488, p.11)

- *MENTAL HEALTH PRACTICES* | Online – 9 November 2016 – ‘**End-of-life and palliative care of patients with drug and alcohol addiction.**’ This literature review attempts to identify current knowledge of the end of life (EoL) care needs of patients with drug and alcohol addiction ... and to identify any existing good practice guidance. The author recommends a discussion about what the term recovery can mean when applied to a person with addiction at the EoL, better recognition of approaching EoL in patients with drug and alcohol addictions, and closer working relationships between palliative care and addictions services. **Abstract:** <https://goo.gl/A71TR2>

Noted in Media Watch 29 August 2016 (#477, p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2016;6(3):392-393. ‘**End-of-life care for people with alcohol and other drug problems: An exploratory study.**’ The problematic use of substances is linked to many forms of chronic and life-threatening conditions, the majority of which affect people in later life. In part as a consequence of population ageing and with evidence suggesting that older people’s substance use is increasing, this complex and heterogeneous group is growing. Thus greater numbers will require palliative care and present new challenges to end-of-life services. **Abstract:** <http://goo.gl/EM7WcD>

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

Gender and geographic differences in Medicare service utilization during the last six months of life

JOURNAL OF WOMEN & AGING | Online – 7 November 2017 – End-of-life issues are important for senior women, particularly rural women, who are more likely than their urban counterparts to live alone. The role of residence as a factor for health-care utilization among Medicare beneficiaries during the last six months of life has yet to be investigated. The purpose of this study is to examine whether service utilization in the last six months of life differs across gender and rurality. The odds of rural beneficiaries using home health .. and/or hospice ... in the last six months of life were lower than urban beneficiaries. Female beneficiaries were more likely to use support services such as hospice ... and/or home health services ... than male beneficiaries. The odds of female beneficiaries using inpatient ... and/or outpatient ... were higher than male beneficiaries. This research is important as we examine the range of health services used during the last six months of life, by gender and rurality. Future research is needed to understand how access to health services, residential isolation, and age- and disease-related factors relate to women's observed greater use of inpatient, outpatient, hospice, and home health services in the last six months of life. **Abstract:** <https://goo.gl/V4es35>

Palliative care in decompensated cirrhosis: A review

LIVER INTERNATIONAL | Online – 7 November 2017 – Decompensated cirrhosis is an illness that causes tremendous suffering. The incidence of cirrhosis is increasing and rates of liver transplant, the only cure, remain stagnant. Palliative care (PC) is used infrequently in patients with decompensated cirrhosis. The allure of transplant as a potential treatment option for cirrhosis, misperceptions about the role of PC and difficulty predicting prognosis in liver disease are potential contributors to the underutilization of PC in this patient population. Studies have demonstrated some benefit of PC in patients with decompensated cirrhosis, but the literature is limited to small observational studies. There is evidence that PC consultation in other patient populations lowers hospital costs and ICU utilization and improves symptom control and patient satisfaction. Prospective randomized control trials are needed to investigate the effects of PC on traditional and patient reported outcomes as well as cost of care in decompensated cirrhosis for transplant eligible and ineligible patient populations. **Abstract:** <https://goo.gl/Sfk4sh>

N.B. Additional articles on palliative and end-of-life care for people living with kidney disease noted in the 4 September 2017 issue of Media Watch (#528, pp.5-6).

Decisions at the end of life: “The inimitable hallmark of the lawyer”?

MEDICAL LAW REVIEW | Online – 7 November 2017 – This case commentary analyses the application of the best interests standard in section 4 of the Mental Capacity Act 2005 [of England & Wales] by the Court in the decision in *Abertawe Bro Morgannwg University Local Health Board v RY (by his litigation friend the official solicitor) and CP...* It evaluates the way in which the law impacted on how clinical decisions in respect of *RY* were made and identifies systemic concerns arising from the case. **Abstract:** <https://goo.gl/6hZdTE>

Noted in Media Watch 12 June 2017 (#516, p.3):

- U.K. (Wales) | *The Daily Mail* – 9 June 2017 – ‘**Doctors film elderly patients to show they should be left to die: Judge warns against “invasive” tactics and fears footage could be edited to mislead the courts.**’ A senior judge has condemned hospitals that film desperately ill patients to use as evidence that they should be allowed to die. Mr. Justice Hayden rebuked doctors after an National Health Service board used a video of an 81-year-old man to persuade the Court of Protection that his life support should be withdrawn. In a landmark ruling, the judge told the health service to stop making videos of patients unless they could show “strong and well-reasoned justification.” The Abertawe Bro Morgannwg health board in South Wales submitted the film to gain legal permission to withdraw a patient’s ventilation and other life-sustaining treatment, and only provide him with palliative care. <https://goo.gl/iZ2QeC>

No matter the species

U.S. and U.K. veterinary medicine schools: Emphasis on end-of-life issues

MORTALITY | Online – 6 November 2017 – The purpose of this research is to determine the status of dying, death and bereavement within the curricula of veterinary medicine schools in the U.S. and the U.K. Data were obtained via a mailed questionnaire (80% U.S. and 86% U.K. return rates). Results revealed that over 96% of schools have offerings related to end-of-life (EoL) issues, with nearly 100% of students exposed to these offerings. The average number of hours spent on EoL issues is 7 (U.S.) and 21 (U.K.). Topics covered most often are euthanasia, analgesics for chronic pain, and communication with owners of dying animals. Veterinary schools overwhelmingly note that dying, death and bereavement are important topics. It might be helpful to veterinary medicine students if their own feelings regarding dying and death were addressed early in the curriculum and throughout class activities and clinical work. **Abstract:** <https://goo.gl/cgJLdC>

N.B. The parallel to be drawn between the practice and philosophy of hospice and palliative care in humans and how end-of-life care for domestic animals has evolved in recent years has occasionally been highlighted in Media Watch, e.g., the issue of 8 May 2017 (#511, p.9).

“A strange kind of balance”: Inpatient hospice volunteers’ views on role preparation and training

PROGRESS IN PALLIATIVE CARE | Online – 5 November 2017 – There is a paucity of research on the training needs of hospice volunteers. In the U.K., there have been calls for the development of a core curriculum for hospice volunteers, but debate exists around the potential for unnecessary “professionalization” of volunteers, diluting their unique contribution. This qualitative, focus group study explores the views of U.K. inpatient hospice volunteers regarding initial training for role preparation. Following thematic analysis, six themes emerged: 1) Role preparation; 2) Common sense and life experience; 3) Role challenges; 4) Benefits and boundaries of training; 5) Training content; and, 6) Training delivery. This study will inform local practice, shaping the education and support of future volunteers, and adds to the wider evidence-base surrounding the development of this crucial group within the hospice workforce. **Abstract:** <https://goo.gl/VsMf55>

Noted in Media Watch 20 March 2017 (#504, p.6):

- *BMC PALLIATIVE CARE* | Online – 14 March 2017 – **‘To be a trained and supported volunteer in palliative care: A phenomenological study.’** The findings highlight that volunteering is experienced as meaningful and satisfying, and that the volunteers have an independent and important role to play among seriously ill or dying people in the palliative care team by providing practical help and emotional support. **Full text:** <https://goo.gl/AJVbNh>

N.B. Additional articles on hospice and palliative care volunteers are noted in this issue of Media Watch.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *INTERNATIONAL JOURNAL OF LAW & PSYCHIATRY*, 2017;55(November-December):37-44. **‘Euthanasia requests in a Canadian psychiatric emergency room: Part 1 of the McGill University euthanasia in psychiatry case series.’** Euthanasia was decriminalized in Quebec in December 2015, and Canada-wide in June 2016. Both the Provincial and Federal legislation have limited the right to medical assistance in dying (MAiD) to end-of-life cases; which makes MAiD inaccessible to most patients solely suffering from psychiatric illness. While some end-stage anorexia nervosa or elderly patients may meet the end-of-life criterion because of their medical comorbidities or their age, repeated suicide attempts or psychotic disorganization would not qualify since they would not be seen as elements of an illness leading to a foreseeable “natural death.” This is in contradiction to other jurisdictions, such as Belgium and The Netherlands as well as the eligibility criteria stated in the Supreme Court of Canada’s decision in *Carter v. Canada...* **Abstract:** <https://goo.gl/UtH6Dp>

Cont.

- *LAWS*, 2017;6(4):23. **‘Barriers to physician aid in dying for people with disabilities.’** Terminally ill people with disabilities face multiple barriers when seeking physician aid in dying (PAD) in the U.S. The first is legality. Efforts to legalize the practice have been thwarted in dozens of states in part due to vocal opposition by advocates for people with disabilities who contend that legalized aid in dying discriminates against and harms people with disabilities by leading to their premature and unnecessary deaths. Some disability rights advocates disagree with their colleagues, however, and support legalization on the ground that it promotes autonomy and independence at the end of life. For proponents, legalization in six states is proving to be an illusive victory. Emerging reports from the states where PAD is legal suggest that people with disabilities may face special and impenetrable barriers when seeking legal aid in dying. This article identifies four such barriers: 1) Procedural protections embedded in PAD statutes; 2) Physician objection; 3) Cost; and, 4) A rule pertaining to California veterans. The article calls for additional study to determine the extent to which these barriers have a disparate impact on care options available to terminally-ill people with disabilities. **Full text:** <https://goo.gl/mzuKaT>
 - *MEDICAL LAW REVIEW* | Online – 7 November 2017 – **‘Is it now institutionally appropriate for the courts to consider whether the assisted dying ban is human rights compatible? *Conway V Secretary of State for Justice.*’** Noel Conway has ultimately been granted permission to apply for judicial review to seek a declaration under section 4(2) Human Rights Act 1998 that section 2(1) Suicide Act 1961 is incompatible with his right to respect for private life under Article 8(1) ECHR. Both decisions in the application process are significant. They attempt to deal with the qualitative elements in the reasoning of Lords Neuberger, Mance and Wilson, in *Nicklinson v Ministry of Justice*: what Parliament is required to have done to have “satisfactorily addressed” the question of relaxing or modifying section 2(1) Suicide Act. In failing to consider the explicit use of qualitative reasoning, both courts fail to interpret *Nicklinson* properly – that Parliament must change the law, with a declaration of incompatibility likely if it failed to do so. The Court of Appeal was correct to overrule the High Court’s unqualified approach to whether it was now institutionally appropriate for a court to consider issuing a declaration of incompatibility, for the purposes of granting permission to apply for judicial review. However, the Court of Appeal directly signals their belief that a range of primary evidence bears out a system of assisted suicide for those in Mr. Conway’s position could feasibly be devised. This question though, as to evidence of a feasible system in the future, is irrelevant to whether permission to apply for judicial review should be granted to argue it is institutionally appropriate to make a declaration of incompatibility regarding current legislation. This is a problem *Nicklinson* has made for assisted dying and incompatibility debates. **Abstract:** <https://goo.gl/aB2DtG>
- N.B.** Additional articles on the Conway case are noted in the 6 November 2017 issue of Media Watch (#537, p.12).
- *MEDSCAPE* | Online – 9 November 2017 – **‘When dying becomes unaffordable.’** Only 1 month after California proposed legislation that would make it the fifth state to allow physician-assisted dying (PAD) in the U.S., the company manufacturing the drug most commonly used in this process, secobarbital, dramatically raised the cost of the drug. The price tag of ending one’s life has jumped from around \$200 up to \$3000 or higher. Funding from state plans will vary... For example, in Oregon, Medicaid partly covers the procedure using money from the state-funded allowance, but not from the federal portion. In 2009, a lethal dose of secobarbital (100 capsules) cost less than \$200 (less than \$2 per capsule), a fraction of what it is now. During the next 6 years, the price gradually crept up to \$1,500 until its purchase by Valeant Pharmaceuticals, which promptly doubled the cost. Whether or not the timing with California’s law was deliberate, some have called the move “exploitive,” in that secobarbital is a generic drug that has been on the market for about 80 years. More importantly, by 2015, secobarbital had become the only viable option for patients seeking to end their lives, and doubling the price suddenly put a heavy financial burden on the price of dying. **Full text:** <https://goo.gl/igEWCf>

Journal Watch

The landscape of scientific research is changing. Contributing factors include the evolution in recent years of what is widely-termed “predatory journals.” ‘Journal Watch’ will be an occasional feature of this weekly report, alerting recipients of Media Watch to trends in publishing that have the potential to negatively impact on evidence-based practice and, in turn, undermine the trust and confidence of the general public in scientific research. Selected articles on trends in scientific publishing are noted in the 6 November 2017 issue of Media Watch (#537, p.13). **BRA**

Why developing countries are particularly vulnerable to predatory journals

SOUTH AFRICA | *The Mail & Guardian* (Johannesburg) – 8 November 2017 – Every day academics wade through emails riddled with spelling errors promising almost immediate publication of their research. These publications assure the reader that they can skip the tough realities of rejections and revisions. Just a simple click of the submission button, they promise, and within a month – or even just a few days – the article will be published. No need to worry about rigorous peer review (or indeed any form of review): these journals are willing to publish absolutely anything in exchange for handsome sums of money. These are predatory publications, and they’re rife. They’re different from mainstream journals because they charge exorbitant fees to publish the articles they solicit, and they don’t follow any of the quality assurance processes expected in academic publication. Academics in the developing world have become a favourite target for these journals, and many seem to be falling into the trap. We need to ask why. The main reason for this is that there’s a systemic problem – academic publication is too often linked to performance targets or the accrual of incentive funding. For as long as this is the case, academics will take short cuts. This is certainly the case in South Africa, where academics are often encouraged to publish because this will increase the subsidy the institution receives from the state rather than because it is a university’s task to contribute to knowledge creation. <https://goo.gl/U5EWmW>

Noted in Media Watch 14 August 2017 (#525, p.16):

- *SOUTH AFRICAN JOURNAL OF SCIENCE*, 2017;113(7/8):1-9. ‘**The extent of South African authored articles in predatory journals.**’ The authors present a first estimate of the extent of predatory publishing amongst South African academics. This estimate is based on an analysis of all South African authored papers that qualified for subsidy over the period 2005 to 2014. The analysis shows that 4,246 South African papers were published in 48 journals which the authors classified (as either being probably or possibly predatory. **Full text:** <https://goo.gl/pJazoc>

Letter to the Editor

Predatory’ science journals

U.S. | *The New York Times* – 2 November 2017 – ‘In academia, a predatory twist in publishing’ [sic] ... aligns two worrisome trends: the ever-increasing need to publish or perish and the commercialization of science.¹ Each trend on its own has been around for a while, but predatory journals effectively ply the two together for goals that have nothing to do with traditional scientific values. Reputable, peer-reviewed science supports healthy, productive, developing societies. When done best, it provides solutions for a multitude of problems facing the world. As an academic and publisher, I understand the need to publish. But given the political climate – claims of fake news, science denialism and blatant obfuscation of fact – we need to be especially diligent about ensuring that academic publishing adheres to the highest standards. This is even more serious and urgent given the potential cuts to existing science standards, funding and the general value of science in issues facing our everyday lives. <https://goo.gl/ZF9tuD>

1. ‘Many academics are eager to publish in worthless journals,’ *The New York Times*, 30 October 2017. [Noted in the 6 November 2017 issue of Media Watch (#537, p.13)] <https://goo.gl/wbh42J>

N.B. The writer is chief scientific officer, science publications, at the New York Academy of Sciences and editor in chief of *Annals of the New York Academy of Sciences*.

Academic journal publishing is headed for a day of reckoning

U.S. | The Conversation – 5 November 2017 – Imagine a researcher working under deadline on a funding proposal for a new project. This is the day she's dedicated to literature review – pulling examples from existing research in published journals to provide evidence for her great idea. Creating an up-to-date picture of where things stand in this narrow corner of her field involves 30 references, but she has access to only 27 of those via her library's journal subscriptions. Now what? There isn't time to contact the three primary authors to get copies directly from them. Interlibrary loan will take too long. She could try other sites that host academic papers – such as ResearchGate and Sci-Hub – but access to particular articles isn't assured and publishers are cracking down on what they call copyright violations. This fictitious example illustrates the quandary in which many researchers find themselves today. Access to journals is crucial for how they do their work. But few research libraries can afford all the journal subscriptions needed by all of their faculty for all occasions. As the dean of libraries at a state school, the author contends that the economic model for academic journal publications is broken. As scholars are handicapped by limited access to the corpus of research in their fields, scientific progress is restricted and slows, and society ultimately loses. **Full text:** <https://goo.gl/9Enum5>

Media Watch: Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/3oecYD>

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

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

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

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

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/lXO4mD>

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

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>

[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>

[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <https://goo.gl/IOSNC7>

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>

[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W>

[Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d119K>

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

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.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Barry R. Ashpole
Guelph, Ontario CANADA

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