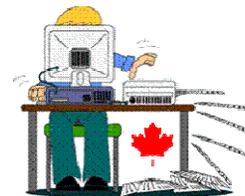


Media Watch...

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.

4 September 2017 Edition | Issue #528



Compilation of Media Watch 2008-2017 ©

Compiled & Annotated by Barry R. Ashpole

Effecting change in the illness experience: Scroll down to [Specialist Publications](#) and 'Advanced care planning: Pearls, perils, pitfalls, and promises' (p.10), in *Journal of Oncology Practice*.

Canada

Family caregivers in British Columbia feeling more depressed, angry: Report

BRITISH COLUMBIA | CBC News (Vancouver) – 30 August 2017 – A new report from the province's seniors advocate says more and more family caregivers are feeling distressed in their role, despite receiving home support – some to the point of feeling as though they can't keep up with their duties.¹ More than 31% caregivers in that category felt angry or depressed, according to the 2016 findings – up from 29% in 2015. At the same time, the report said supports available to those caregivers are less accessible than they were two years ago. There are about one million "informal" caregivers in the province, according to Statistics Canada. They are predominantly

family members caring for their mothers, fathers, spouses or adult children. This year's report focused on the 26,310 who are receiving publicly subsidized home support. <https://goo.gl/1agLcm>

[Specialist Publications](#)

'Caregiving and caregivers: An important part of the healthcare team' (p.8), in *Home Healthcare Now*.

'The development of practice guidelines for a palliative care multidisciplinary case conference' (p.12), in *Journal of Pain & Symptom Management*.

1. 'Caregivers in Distress: A Growing Problem,' Office of the Seniors' Advocate, British Columbia, August 2017. <https://goo.gl/zi8hzF>

N.B. There is no mention of home palliative care in the report of the Seniors' Advocate. For an American perspective in the role and responsibilities of the family caregiver scroll down to [U.S.A.](#) and 'Home health care: Shouldn't it be work worth doing?' (p.3), in *The New York Times*. **BRA**



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.18.

Disasters don't stop palliative care

BRITISH COLUMBIA | *The Prince George Citizen* – Accessed 30 August 2017 – Those requiring acute care or assisted living were all placed out of the general population when more than 10,000 evacuees were registered in Prince George over the last few weeks because of wildfires. There were about 90 people who required special care and placed at Gateway Lodge, about 60 from the Williams Lake Seniors Village were relocated to the residence at University of Northern British Columbia ... while others needing acute care were placed in hospital. Among those needing special care were four people who were placed in the Prince George Hospice Rotary House. “End of life (EoL) journeys don't pause because of disasters,” Donna Flood, executive director of the Prince George Hospice Society, said about those who, at the end of their lives, were evacuated from Williams Lake to Prince George. Flood said she couldn't imagine someone going through their EoL while family members are trying to come to grips with the anticipated loss, and then there's a threat to the home on top of it all which results in everyone being uprooted for safety's sake. <https://goo.gl/31jNLv>

N.B. Scroll down to [U.S.A.](#) and 'Hurricane Harvey: The impact from a hospice and palliative care perspective' (p.4).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | CBC News – 1 September 2017 – ‘**Docs in north-east first to get provincially funded training in medically assisted dying.**’ Under the legislation, patients who request Medical Assistance in Dying (MAiD) must be assessed by two independent physicians or nurse practitioner to determine their eligibility. According to the North East Local Health Integration Network just ten doctors and nurse practitioners provide MAiD in the region. But that should change in the near future. The Ministry of Health & Long Term Care is providing funding for training for more doctors and nurse practitioners to provide MAiD. The North East will be the first site to offer this. The comprehensive training will be provided from the Canadian Medical Association, and will include assessment, technical aspects, law, self care, social impacts and managing family. <https://goo.gl/B5PNDb>

[Specialist Publications](#)

‘**Medical Assistance in Dying in Canada: Focus on rural communities**’ (p.16), in *Journal for Nurse Practitioners*.

[U.S.A.](#)

Will you need a nursing home during lifetime? Chances are yes, study says

FLORIDA | *The Miami Herald* – 1 September 2017 – What are the average American's chances of needing a nursing home in their lifetime? A lot higher than previously estimated, says a recent study...¹ Among persons 57- to 61-years-old about 56% will stay in a nursing home at least one night during their lifetime – compared to earlier estimates that ranged from 35 to 45%... The higher rate is likely due to an increase in short stays in nursing homes. Researchers found that nursing home stays of 21 nights or fewer rose from 28% in 1998 to nearly 34% in 2010. <https://goo.gl/WfGXak>

1. ‘Distribution of lifetime nursing home use and of out-of-pocket spending,’ *Proceedings of the National Academy of Sciences*, published online 28 August 2017. **Abstract:** <https://goo.gl/RZeQWZ>

Noted in Media Watch 21 August 2017 (/526, p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 August 2017 – ‘**Palliative care consults in U.S. nursing homes: Not just for the dying.**’ Short- and long-stay nursing home (NH) residents with palliative care consults differed not only, in many respects, from NH residents generally, but also from each other. Despite these differences, half of short-stay and 57% of long-stay residents were alive six months after initial consults. **Abstract:** <https://goo.gl/fNE6cX>

End-of-life talks taking backseat to promises of immunotherapy miracles

KAISER HEALTH NEWS | Online – 1 September 2017 – “In the oncology community, there’s this concept of ‘no one should die without a dose of immunotherapy,’” said Dr. Eric Roeland, an oncologist and palliative care specialist. “And it’s almost *in lieu* of having discussions about advance-care planning, so they’re kicking the can down the street.” <https://goo.gl/j6JdJN>

\$5 million appropriation will fund end-of-life care model in New Jersey

NEW JERSEY | *The Teaneck Daily Voice* – 1 September 2017 – The budget appropriation ... will support ... eight key initiatives, including the development of a model for end-of-life-care (EoLC) 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 end-of-life 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. It also revealed New Jersey residents spend 44% more days in the intensive care unit compared to the average American and 30% more days in the hospital in the last six months of life. <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, June 2013. [Noted in Media Watch 11 June 2013 (#310, p.4). <http://goo.gl/aRxuH6>

Home health care: Shouldn’t it be work worth doing?

THE NEW YORK TIMES | Online – 29 August 2017 – Do you know who is going to care for you when you are old and frail? By current standards, it’s likely to be a middle-aged immigrant woman, with maybe a high school education and little if any training, making \$20,000 a year. And that’s if you are lucky. If you live in rural America, you may already have a hard time finding somebody to look after you. Paul Osterman of the Massachusetts Institute of Technology’s Sloan School of Management calculates that if nothing is done to draw more workers into the field, there will be a shortage of at least 350,000 paid care providers by 2040. How to provide long-term care for a fast-aging population poses one of the more convoluted challenges of the American labor market. Care providers – home health aides, personal care attendants and certified nursing assistants, in the government’s classification – are expected to be among the nation’s fastest-growing occupations. The Department of Labor’s economists expect about a million more will be added from 2014 to 2024. <https://goo.gl/9zdRe3>

Specialist Publications

‘Young adults’ perspectives on advance care planning’ (p.10), in *American Journal of Hospice & Palliative Medicine*.

‘How medicine has changed the end of life for patients with cardiovascular disease’ (p.9), in *Journal of the American College of Cardiology*.

‘Homing in on the social: Systems-level influences on overly aggressive treatments at the end of life’ (p.12), in *Journal of Pain & Symptom Management*.

‘Repeal of the Affordable Care Act will negatively impact children at end of life’ (p.15), in *Pediatrics*.

‘American Academy of Pediatrics Policy Statement: Guidance on forgoing life-sustaining medical treatment’ (p.15), in *Pediatrics*.

Cont.

Related

- MISSOURI | *The Herald Palladium* (St. Joseph) – 27 August 2017 – **‘Resources are available for long-distance caregiving.’** National statistics from the Family Caregiver Alliance ... showed that 43.5 million Americans provided regular, unpaid care to someone needing ongoing help. Of these, 5-7 million were long-distance caregivers. The number of long-distance caregivers is projected to double by 2020. While most caregivers, about 66%, live within 10 miles of the person they’re caring for, nationally, long-distance caregivers live an average of 450 miles from their care recipients; or approximately seven hours travel time. <https://goo.gl/5Pp1KQ>



TEXAS NON-PROFIT
HOSPICE ALLIANCE

Personal communication

Hurricane Harvey: The impact from a hospice and palliative care perspective



With Hurricane Harvey, we have really experienced two different kinds of storms and thus impacts on our communities. When it became clear that the hurricane was heading our way, coastal communities evacuated which meant that our hospices needed to prepare patients, know which home care patients were leaving, where they were going, and then coordinating care with other hospices in the areas they were evacuating to. The Texas Non Profit Hospice Alliance is an Alliance of non-profit hospices all across the state that works together and supports one another very closely and our members in unaffected areas were at the ready to receive patients who were evacuating to their areas. Staff in the path of the hurricane such as at Hospice of South Texas in Victoria remained behind to care for patients. The small coastal town of Rockport took a direct hit when the hurricane came ashore At AIM Hospice Many staff having experienced personal losses from the storm have been driving back and forth to care for patients who were not able to or did not wish to leave.

In Houston and the east Texas community of Orange the situation has been flooding from unprecedented rains is still unfolding. Hospice teams at Houston Hospice and Southeast Texas Hospice in Orange were communicating with home care patients via phone, but are unable to get to homes due to the extreme flooding. Staff has been working around the clock in Houston Hospice’s inpatient center which miraculously did not flood. The magnitude of the flooding right now means that patients and staff alike have been flooded and displaced. Much help will be needed to find and care for displaced patients, to ramp services back up, and to give medical, spiritual and counseling assistance to the patients and families who are going through so much with this unprecedented storm.

The staff at all of these hospices has been amazing and under extremely difficult circumstances have moved heaven and earth to care for patients and families.

The members of Alliance are united in the belief that the non-profit hospice model best reflects the caring culture that exists in our Texas communities – where neighbors join together to focus their energies on comprehensive and compassionate care for their patients and their families. That caring culture was seen throughout the ordeal that was Hurricane Harvey.

We have created the Texas Non Profit Hospice Alliance Disaster Relief Fund to help the affected member hospices ramp back up and to also assist staff that may have lost homes or been otherwise impacted by the storm.¹ **Kirsti Krejs, President/CEO, Texas Non-Profit Hospice Alliance, 1 September 2017**

1. Texas Non-Profit Hospice Alliance: <https://goo.gl/KDWir9>

Noted in Media Watch 12 December 2016 (#491, p.1):

CANADA | TV Ontario – ‘Shared Values’ (Toronto) – 8 December 2016 – **‘Emergency aid workers save lives, but can they make death more comfortable, too?’** Emergency responders have always had to confront death at natural disaster sites and in warzones, yet palliative care (PC) has never been a priority for aid groups operating in such places. Their first priority is to save lives: no widely adopted guidelines exist to help them address the reality of death. <https://goo.gl/lojYL3>

International

End-of-life care in England

St. Joseph's Hospice in Sefton banned from accepting patients

U.K. (England) | BBC News – 30 August 2017 – St. Joseph's Hospice in Merseyside was placed in special measures after inspectors discovered issues including some ineffective monitoring of pain. The Care Quality Commission also found the way some medicines were given put patients at risk and recorded examples of dignity not being respected. The hospice has had conditions placed on its registration including "preventing further admissions until it can demonstrate significant improvement." The 29-bed unit ... was accommodating 25 people at the time of the inspection in July... Staff did not always follow the principles of the Mental Capacity Act 2005 when people were unable to give consent, the health watchdog said. The hospice will be kept under review and inspected again within six months. <https://goo.gl/yJg1d9>

Specialist Publications

'Palliative care in Africa: A scoping review from 2005–2016' (p.13), in *Lancet Oncology*.

'Trend analysis of end-of-life care between hospice and non-hospice groups of cancer patients in Taiwan for 2002–2011' (p.14), in *Medicine*.

Most Australians are rubbish at dying

AUSTRALIA (New South Wales) | *The Sydney Morning Herald* – 26 August 2017 – Don't take it personally: so are most people who live in the developed world. Anxiety about death has grown deep roots. Dying is something that has become hidden away and to be desperately resisted at all costs. Advances in public health and medicine may have led to giant leaps in life expectancy, but they've also created a dependency on treatment and intervention "at all costs" as we try to deny the inevitability of death. And, in the vacuum created by our disconnection from dying, we have allowed fear, misinformation and myth to flourish. Death is portrayed by an ill-informed media as inherently painful, undignified and traumatic – a depiction, incidentally, that is completely at odds with the experience of the vast majority of the people we care for in our palliative care services. Is it any wonder that public support for assisted suicide is as high as it is? <https://goo.gl/zzMHDY>

Specialist Publications

Advanced chronic liver disease in the last year of life: A mixed methods study to understand how care in a specialist liver unit could be improved

BMJ OPEN | Online – 29 August 2017 – Findings reflect the complicated clinical picture surrounding the provision of care of people with cirrhosis in their last year of life. The authors demonstrate that patients have a high symptom burden, increasing number of admissions in their last 3 months of life and a focus on active, disease-directed treatments. As with previous studies, they highlight poor palliative care (PC) provision, in which discussions about prognosis and resuscitation orders were only raised in the last few days of life and referrals to PC were made very close to death. Liver clinicians have difficulties in initiating discussions regarding prognosis, do not engage in parallel planning for potential deterioration as well as recovery, and have a limited knowledge of PC. Studies suggest that uncertainty is an important barrier to anticipatory care planning in advanced liver disease. The authors' qualitative data further illustrate how five key factors interact as barriers to PC. Although liver clinicians may wish to refer patients to PC earlier, active treatment is usually the *de facto* choice unless patients themselves specifically raise the topic. **Full text:** <https://goo.gl/EcCGeB>

Cont.

Related

- *BMJ OPEN* | Online – 1 September 2017 – ‘**How can primary care enhance end-of-life care for liver disease? Qualitative study of general practitioners’ perceptions and experiences.**’ GPs [i.e., study participants] expressed a desire to be more closely involved in end-of-life care for patients with liver disease, but identified a number of factors that constrained their ability to contribute. These fell into three main areas; 1) Those relating directly to the condition, (symptom management and the need to combine a palliative care approach with ongoing medical interventions); 2) Issues arising from patients’ social circumstances (stigma, social isolation and the social consequences of liver disease); and, 3) Deficiencies in the organisation and delivery of services. **Abstract:** <https://goo.gl/Yo3xQh>

Noted in Media Watch 3 July 2017 (#519, p.12):

- *NEWS MEDICAL* | Online – 29 June 2017 – ‘**New study uncovers low rates of palliative care referral in patients with end-stage liver disease.**’ A new study has uncovered low rates of referral for palliative care (PC) in U.S. patients with end-stage liver disease, although rates have been slowly increasing over time.¹ The study found certain socioeconomic and ethnic barriers may hinder access to PC services. Historically, only a limited number of affected patients have used PC. Of 39,349 patients in this analysis, PC consultations were performed for 1,789 of patients. **Abstract:** <https://goo.gl/iFcQTp>

1. ‘Palliative care access for hospitalized patients with end stage liver disease across the U.S.,’ *Hepatology*, published online 29 June 2017. **Abstract:** <https://goo.gl/gKtDRR>

- *GASTROINTESTINAL NURSING* | Online – 20 June 2017 – ‘**Sooner rather than later: Early hospice intervention in advanced liver disease.**’ Palliative care provision for these patients is often poor, with no clear national guidance for end-stage liver disease. This article describes a pilot project conducted to assess the impact of early hospice intervention on patients’ wellbeing and experience. Patients remained under acute hospital management and were seen by the hospice’s specialist nurse practitioner on a monthly basis and referred into hospice services as needed. **Abstract:** <https://goo.gl/U4CFvW>

A qualitative inquiry into the barriers and facilitators to achieving home death

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 1 September 2017 – Three overarching themes, further divided into a total of 12 sub-themes were identified. The three themes were 1) Managing people; 2) Education; and, 3) Planning. The managing people theme included sub-themes of patient preferences and family influences; the education theme encompassed knowledge and training, perceptions of death and communication, and the planning theme contained seven sub-themes, including coordination, resources and cost. Of particular significance was the identification of the fear and stigma associated with death among doctors, patients and their families serving as a barrier to home death, not previously identified in the literature. Additionally, the importance of social networks and resource provision were highlighted as key in influencing patient death at home. **Abstract:** <https://goo.gl/g7qP5R>

N.B. Additional articles on barriers to achieving home death are noted in the 7 August 2017 issue of Media Watch (#524, p.9).

Effectiveness of bereavement counselling through a community-based organization: A naturalistic, controlled trial

CLINICAL PSYCHOLOGY & PSYCHOTHERAPY | Online – 29 August 2017 – Bereavement counselling for elevated- and high-risk bereaved persons has a beneficial effect on grief symptoms over 18 months. Preliminary indications suggest no marked difference in the effectiveness of bereavement counselling for elevated versus high levels of complicated grief. Professionally trained volunteer counselling by a non-profit organization complements professional services. **Abstract:** <https://goo.gl/6Kcgoa>

Palliative care dentistry: Focusing on quality of life

COMPENDIUM OF CONTINUING EDUCATION IN DENTISTRY, 2017; 38(8):529. Palliative care (PC) dentistry is the management of patients with progressive, far-advanced disease for whom the oral cavity has been compromised either by disease or by treatment. The focus of care is on the immediate quality of life. Typically, the PC team neglects to include a dentist despite many patients under its care, including those with cancer, exhibiting oral problems such as xerostomia, candidiasis, mucositis, and loss of masticatory function. This article discusses the oral care of patients with terminal illnesses, many of whom have oral maladies that negatively impact quality of life. Treatment options for these patients will be outlined.

Abstract: <https://goo.gl/WrxwgF>

Noted in Media Watch 5 September 2016 (#478, p.17):

- *PEDIATRIC DENTISTRY*, 2016;38(4):295-299. ‘**Preparing the pediatric dentist for palliative and end-of-life care.**’ The purpose of this clinical article was to highlight palliative care scenarios in pediatric dentistry and provide actionable resources to empower pediatric dentists to gather health care information, make informed ethical decisions, promote patient- and family-centered care, and prepare dentists and their dental teams for episodes of death and bereavement when providing a dental home to patients with life-threatening and complex chronic conditions. **Abstract:** <http://goo.gl/knkvPQ>

End-of-life care in France

“It was the only thing I could hold onto, But...”: Receiving a letter of condolence after loss of a loved one in the ICU: A qualitative study of bereaved relatives’ experience

CRITICAL CARE MEDICINE | Online – 28 August 2017 – Family members of patients who die in the ICU often remain with unanswered questions and suffer from lack of closure. A letter of condolence may help bereaved relatives, but little is known about their experience of receiving such a letter. The objective of the study was to understand bereaved family members’ experience of receiving a letter of condolence. Six themes emerged: 1) A feeling of support; 2) Humanization of the medical system; 3) An opportunity for reflection; 4) An opportunity to describe their loved one; 5) Continuity and closure; and, 6) Doubts and ambivalence. Possible difficulties emerged, notably the re-experience of the trauma, highlighting the absence of further support. **Abstract:** <https://goo.gl/3ikF4n>

Noted in Media Watch 27 June 2016 (#468, p.9):

- *AMERICAN JOURNAL OF CRITICAL CARE*, 2016;25(2):110-117. ‘**Bereavement services offered in adult intensive care units in the U.S.**’ Most survey respondents reported that their ICUs did not offer bereavement follow-up services, and many barriers were noted. When bereavement follow-up care was offered, it was mainly informal (e.g., condolence cards, brochures). ICUs in hospitals with palliative care (PC) were almost eight times more likely to provide bereavement support than were ICUs in hospitals without PC. **Abstract:** <http://goo.gl/48KIL7>

Does the distinctiveness of palliative care research require distinct ethical guidelines?

EUROPEAN JOURNAL OF BIOETHICS, 2017;8(15):31-57. Palliative and end-of-life care (EoLC) is changing, becoming more widespread and improving for patients. Yet, the current literature in the field suggests that the evidence for palliative and EoLC is somewhat limited. Research on treatment decisions, family care, and advance directions are just a few of the areas that need rigorous research efforts. Palliative care (PC) research is essential in order to continue providing effective treatments to those suffering in the last stages of life. Indeed, the goal of good PC research is to relieve suffering and to improve quality of life. Similar to any other field, PC programs must develop on a research base, and patient care will suffer if it is not backed by sound research. However, weighted against this need are some who maintain that the ethical and practical challenges of PC research are unique and insurmountable. This analysis considers if distinct ethical guidelines are needed for PC research. **Abstract:** <https://goo.gl/hhEQ9o>

N.B. Additional articles on research priorities in palliative and end-of-life care are noted in the 7 August 2017 issue of Media Watch (#524, p.12).

End-of-life care in Australia

Telemonitoring via self-report and video review in community palliative care: A case report

HEALTHCARE | Online – 31 August 2017 – Continuous monitoring and management of a person's symptoms and performance status are critical for the delivery of effective palliative care (PC). This monitoring occurs routinely in inpatient settings; however, such close evaluation in the community has remained elusive. Patient self-reporting using telehealth offers opportunities to identify symptom escalation and functional decline in real time, and facilitate timely proactive management. The authors report the case of a 57-year-old man with advanced non-small cell lung cancer who participated in a telehealth trial run by a community PC service. This gentleman was able to complete self-reporting of function and symptoms via iPad although at times he was reticent to do so. Self-reporting was perceived as a means to communicate his clinical needs without being a bother to the community PC team. He also participated in a videoconference with clinical staff from the community PC service and his general practitioner (GP). Videoconferencing with the nurse and GP was highly valued as an effective way to communicate and also because it eliminated the need for travel. This case report provides important information about the feasibility and acceptability of PC telehealth as a way to better manage clinical care in a community setting. **Full text:** <https://goo.gl/Fa6CN7>

Case study

Caregiving and caregivers: An important part of the healthcare team

HOME HEALTHCARE NOW, 2017;35(8). As a home care and hospice consultant, I have written a newspaper column about caregiving in Sarasota County, Florida, a county with a median population age of 55 years ... for many years. The following story is one of many I hear about every year. Sarah, an 86-year-old woman, has moved in with her adult daughter and son-in-law. My involvement began with a phone call from this very distraught couple who were trying to do the right thing and bring a family member into their home when it became obvious she was no longer safe on her own. This move did not occur with much forethought or planning; however, it soon became clear that Sarah was very demanding and difficult, and would not follow the doctor's recommendations nor theirs. The son and daughter-in-law work full time and have two children, ages 14 and 18, living at home. They related that, although Sarah had always been "prickly," her negative behaviors seemed magnified when she moved into their home. The last straw was when Sarah fired the aide they had hired to assist with her personal care. They knew they needed to regroup and develop a long-term plan that would be best for Sarah and her care needs. **Abstract:** <https://goo.gl/ujMm8N>

Related

- *BMC PALLIATIVE CARE* | Online – 30 August 2017 – '**Validation of a modified VOICES survey to measure end-of-life care quality: The CaregiverVoice survey.**' This study validated the Caregiver-Voice survey.... Results demonstrate that key psychometric properties of the VOICES survey, from which it was adapted, were maintained. The uniformity ... of the survey makes it useful for comparing ratings of care between settings and across regions. It represents one common measure that can be standardized across multiple care settings, which can inform local and national quality improvement activities to improve care experience. **Full text:** <https://goo.gl/1VTZ5v>

Noted in Media Watch 6 June 2016 (#465, p.9):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 June 2016 – '**The CaregiverVoice Survey: A pilot study surveying bereaved caregivers to measure the caregiver and patient experience at end of life.**' Most patients received care from multiple settings in the last three months of life, including 60% for which a hospital stay was reported. This study provides preliminary evidence that it is feasible to capture the patient and caregiver experience at end of life using a comprehensive survey. The majority of responses rated care as excellent or very good, although several specific areas for improvement were identified. **Abstract:** <http://goo.gl/dzFXBD>

Cont.

- *PATIENT EDUCATION & COUNSELING*, 2017;100(10):1778-1786. **‘Life values of elderly people suffering from incurable cancer: A literature review.’** The analysis of thirty articles resulted in the extensive description of eight life values: 1) Comfort; 2) Continuity; 3) Humility; 4) Dignity; 5) Honesty; 6) Optimism; 7) Hope; and, 8) Preparedness. These values will play a role in communication and decision-making. Knowledge about life values can help professionals discuss and clarify personal preferences with elderly patients suffering from incurable cancer, contributing to more personalized care and treatment. **Abstract:** <https://goo.gl/Hpd5C3>

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. Advances in medicine have changed how patients experience the end of life (EoL). With longer life spans, there has also been an increase in years lived with disability. The clustering of illnesses in the last years of life is particularly pronounced in patients with cardiovascular disease. At the EoL, patients with cardiovascular disease are more symptomatic, less likely to die at home, and less likely to receive high-quality palliative care (PC). Social determinants have created widening disparities in EoL care. The increasing complexity and duration of care have resulted in an epidemic of caregiver burden. Modern medical care has also resulted in new ethical challenges, for example, those related to deactivation of cardiac devices, such as pacemakers, defibrillators, and mechanical circulatory support. Recommendations to improve EoL care for patients with cardiovascular disease include optimizing metrics to assess quality, ameliorating disparities, enhancing education and research in PC, overcoming disparities, and innovating PC delivery and reimbursement. **Abstract:** <https://goo.gl/aagwMe>

Challenges in providing end-of-life care for people with intellectual disability: Health services access

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 29 August 2017 – Increasing life expectancy for people with intellectual disability is resulting in greater need for end-of-life care (EoLC) services. However, limited knowledge is available regarding what barriers to accessing EoLC support are evident, particularly comparatively across rural and metropolitan locations. Focus group interviews were undertaken with 35 direct-care staff from four rural and two metropolitan locations. Frequency analysis identified 262 statements relating to health services access. Thematic analysis identified four key areas of “isolation,” “support from doctors,” “general health support access” and “internal staffing issues.” Improved access to end-of-life services is urgently required across both rural and metropolitan areas. Development of specialist training and support models for both disability and general healthcare staff may assist to reduce some identified barriers. **Abstract:** <https://goo.gl/p8tfwX>

N.B. Selected articles on end-of-life care for people living with intellectual disabilities are noted in the 28 August 2017 issue of *Media Watch* (#527, pp.10-11).

Do the “brain dead” merely appear to be alive?

JOURNAL OF MEDICAL ETHICS | Online – 28 August 2017 – The established view regarding “brain death” in medicine and medical ethics is that patients determined to be dead by neurological criteria are dead in terms of a biological conception of death, not a philosophical conception of personhood, a social construction or a legal fiction. Although such individuals show apparent signs of being alive, in reality they are (biologically) dead, though this reality is masked by the intervention of medical technology. The authors argue that an appeal to the distinction between appearance and reality fails in defending the view that the “brain dead” are dead. Specifically, this view relies on an inaccurate and overly simplistic account of the role of medical technology in the physiology of a “brain dead” patient. The authors offer an explanation of why the conventional view on “brain death,” though mistaken, continues to be endorsed in light of its connection to organ transplantation and the dead donor rule. **Full text:** <https://goo.gl/LhrX3f>

Cont.

Noted in Media Watch 1 May 2017 (#510, p.13):

- *JOURNAL OF LAW, MEDICINE & ETHICS* | Online – 20 April 2017 – ‘**Shouldn’t dead be dead?: The search for a uniform definition of death.**’ In 1968, the definition of death in the U.S. was expanded to include not just death by cardiopulmonary criteria, but also death by neurologic criteria. The authors explore the way the definition has been modified by the medical and legal communities over the past 50 years and address the medical, legal and ethical controversies associated with the definition at present. **Abstract:** <https://goo.gl/tsF1ol>

Noted in Media Watch 23 January 2017 (#496, p.11):

- *NEUROCRITICAL CARE* | Online – 11 January 2017 – ‘**Physician power to declare death by neurologic criteria threatened.**’ Three recent lawsuits in the U.S. that address declaration of brain death (BD) garnered significant media attention and threaten to limit physician power to declare BD. These cases threaten to: 1) Limit physicians’ power to determine death; 2) Incite families to seek injunctions to continue organ support after BD; and, 3) Force hospitals to disperse valuable resources to dead patients in lieu of patients with repairable illnesses or injuries. **Abstract:** <https://goo.gl/G1QutD>

Advanced care planning: Pearls, perils, pitfalls, and promises

JOURNAL OF ONCOLOGY PRACTICE | Online – 28 August 2017 – With the passing of the Patient Self-Determination Act of 1990, the U.S. government put into place a mechanism to assess routinely whether patients have a living will or advance directive (AD). Despite the 27 years that have passed since the Act’s inception, there remain many challenges in how providers and patients discuss and implement end-of-life plans. Critics have consistently raised concerns that ADs are “fundamentally flawed (as they) presuppose more control over future care than is realistic.” Efforts at improving advance care planning (ACP) processes ... have sprung forth from concerns ... that “advance care planning ought to be the preparation of patients and surrogates to participate with clinicians in making the best possible in-the-moment medical decisions,” with less focus on the presence or absence of the document itself. Part of the challenge with approaching ACP and completion of ADs is that the creation of such documents is a static process that attempts to represent a dynamic, living human being. Although the values of that human being may remain consistent over a lifetime, the health and medical condition of that person often is not stable. Recent consensus panels have attempted to define more clearly what ACP actually is to better implement and measure its impact on outcomes; in addition, more succinct tools to validate ACP engagement behaviors have been recently tested. **Full text:** <https://goo.gl/Gmwnh7>

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 August 2017 – ‘**Young adults’ perspectives on advance care planning.**’ Young adults [i.e., survey respondents] lacked familiarity and knowledge regarding advance care planning (ACP). Although the majority of respondents had positive attitudes and beliefs about ACP, only one-third had talked with their family/loved ones about their wishes for end-of-life care (EoLC). The study findings suggest a strong need to inform and engage young adults in ACP and EoLC discussions. As young adults are likely to become a caregiver for an aging family member, they can have an important role in initiating and facilitating conversations with loved ones and be instrumental in ACP for older adults. **Abstract:** <https://goo.gl/KuJAQv>
- *BMC PALLIATIVE CARE* | Online – 29 August 2017 – ‘**Which online format is most effective for assisting Baby Boomers to complete advance directives? A randomised controlled trial of email prompting versus online education module.**’ This randomized controlled trial demonstrated that neither e-mail prompting nor provision of additional educational material online were sufficient to significantly impact advance directives (ADs) completion rates in this generational group. The authors show that although the online environment, in and of itself, may not yield an increase in completion of ADs at the point of contact, nevertheless, it provides the opportunity for a generation entering older age to contemplate the need and creation of these documents through discussion with family and friends **Full text:** <https://goo.gl/f75A1f>

Cont.

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 1 September 2017 – ‘**Discussion and documentation of future care: a before-and-after study examining the impact of an alternative approach to recording treatment decisions on advance care planning in an acute hospital.**’ Despite patients’ proximity to the end-of-life (EoL) [i.e., patient population studied], there was limited documentation of advance care planning (ACP) and almost no evidence of formalised ACP. The introduction of the Universal Form of Treatment Options was associated with a change in practice on the oncology ward but this was not observed for respiratory patients. A new approach to recording treatment decisions may contribute to improving discussion and documentation about future care but further work is needed to ensure that all patients’ preferences for treatment and care at the EoL are known. **Abstract:** <https://goo.gl/uHgsUa>
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 1 September 2017 – ‘**Patient values informing medical treatment: a pilot community and advance care planning survey.**’ The authors used a locally developed survey tool, ‘What Matters Most,’ to identify values. Choices presented were: maintaining dignity, avoiding pain and suffering, living as long as possible, and remaining independent. Participants rated the importance of each and then selected a main priority for their doctor. Participant groups were a purposive sample of 382 lay people from the general population and 100 attendees at an advance care planning (ACP) clinic. Living as long as possible was considered to be less important than other values for ACP patients and for the general population. Only 4% of ACP patients surveyed and 2.6% of our general population sample selected “living as long as possible” as their top priority for medical treatment. **Abstract:** <https://goo.gl/cAjD7D>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 30 August 2017 – ‘**Outcomes that define successful advance care planning: A Delphi panel consensus.**’ Standardized outcomes that define successful advance care planning (ACP) are lacking. This study convened a Delphi panel consisting of 52 multidisciplinary, international ACP experts including clinicians, researchers, and policy leaders from four countries. The authors conducted literature reviews and solicited attendee input from 5 international ACP conferences to identify initial ACP outcome constructs. In 5 Delphi rounds, they asked panelists to rate patient-centered outcomes on a 7-point “not-at-all” to “extremely important” scale. The authors calculated means and analyzed panelists’ input to finalize an Organizing Framework and outcome rankings. Panelists raised caution about whether “care consistent with goals” can be reliably measured. **Abstract:** <https://goo.gl/4epYGB>
- *JOURNAL OF POST-ACUTE & LONG TERM CARE MEDICINE*, 2017;18(9):741-745. ‘**Standardizing protection of patients’ rights from POLST to MOELI...**’ The Physician Orders for Life-Sustaining Treatment (POLST) has evolved over the years. For example, because many states allow advanced practice nurses and qualified physician assistants to sign and enter the form in patients’ medical records, several states replaced “Physician” with “Medical” or “Provider.” At the same time, “life-sustaining treatment” suggests that the form is intended to guide only treatments designed to prolong life without addressing goals of patients who might not want this outcome. The authors propose changing the name to the more inclusive and accurate Medical Orders for End-of-Life Intervention (MOELI). **Abstracts:** <https://goo.gl/DyRgcC>
- *SUPPORTIVE CARE IN CANCER* | Online – 28 August 2017 – ‘**Patient autonomy and advance care planning: a qualitative study of oncologist and palliative care physicians’ perspectives.**’ The ethical assumptions regarding patient autonomy embedded in academic literature and policy documents relating to advance care planning (ACP) are disconnected from the realities of clinical care. Medical norms and professional boundaries surrounding “good deaths” have a greater influence on care than patient preference. ACP programs, therefore, may be rejected by healthcare professionals as irrelevant to care or may have the unintended consequence of limiting patient autonomy when used as a professional tool to encourage a “right” way to die. A singular focus on bureaucratic ACP programs, which reduce patient autonomy to a “tick box” exercise, may fail to enhance end-of-life care in any meaningful way. **Abstract:** <https://goo.gl/8nfLCV>

End-of-life care in Canada

The development of practice guidelines for a palliative care multidisciplinary case conference

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 1 September 2017 – In Ontario, the authors identified that few hospitals have developed multi-disciplinary case conferences or forums for discussion of patients with palliative care (PC) issues. A provincial survey as well as a multidisciplinary cancer conference symposium identified Multidisciplinary Case Conferences (pMCCs) as a priority. A literature search focusing on pMCCs and their implementation was completed as well as a current state assessment (survey and interviews) to understand challenges with existing pMCCs in Ontario. A Working Group was then assembled to draft a recommendation report that was finalized by an Expert Panel. 22 articles were identified and 10 were utilized by the Working Group to create a framework for the pMCC guideline. The current state assessment identified substantial variability in pMCC structure and function. The Expert Panel made recommendations about meeting format (multidisciplinary discussion encouraged), frequency (at least every 2 weeks), type of cases to present, attendees (PC, nursing, primary care, social work, and community nursing), provider roles and responsibilities, and institutional requirements (pMCC coordinator, meeting room and videoconference capability). All patients (not just those with cancer) with PC needs were to be discussed at the pMCC and pMCCs should serve as a crucial link between the hospital and community. **Abstract:** <https://goo.gl/eMmv7e>

Homing in on the social: Systems-level influences on overly aggressive treatments at the end of life

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 30 August 2017 – The American medical system is programmed to a default setting of aggressive care for the terminally ill. Institutional norms of decision-making have been shown to promote high intensity care, regardless of consistency with patient preferences. There are myriad factors at a system, clinician, surrogate, and patient level that drive the culture of overly aggressive treatments in American hospitals. The interviews [with 42 internal medicine physicians across three American academic medical centers] revealed many factors that contributed to overly aggressive treatments at the end of life. Systemic factors, which describe underlying cultures (including institutional, professional, or community-based cultures), typical practices of care, or systemic defaults which drive patterns of care, manifested its influence both directly as well as through its impact on patient, surrogate, and physician behaviors and attitudes. **Abstract:** <https://goo.gl/8GMivj>



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>

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Palliative care and management of troublesome symptoms for people with chronic obstructive pulmonary disease

THE LANCET | Online – 2 September 2017 – People with advanced chronic obstructive pulmonary disease (COPD) have distressing physical and psychological symptoms, often have limited understanding of their disease, and infrequently discuss end-of-life (EoL) issues in routine clinical care. These are strong indicators for expert multidisciplinary palliative care (PC), which incorporates assessment and management of symptoms and concerns, patient and caregiver education, and sensitive communication to elicit preferences for care towards the EoL. The unpredictable course of COPD and the difficulty of predicting survival are barriers to timely referral and receipt of PC. Early integration of PC with respiratory, primary care, and rehabilitation services, with referral on the basis of the complexity of symptoms and concerns, rather than prognosis, can improve patient and caregiver outcomes. Models of integrated working in COPD could include: services triggered by troublesome symptoms such as refractory breathlessness; short-term PC; and, in settings with limited access to PC, consultation only in specific circumstances or for the most complex patients. **Abstract:** <https://goo.gl/4YQzYT>

Noted in Media Watch 12 June 2017 (#516, p.6):

- *CLINICAL MEDICINE* | Online – 1 June 2017 – “**High-risk**” patients with chronic obstructive pulmonary disease have a poor prognosis and need to be able to access palliative care services.’ The prognosis for this group is poor, with almost half dying within a year, yet only 37% [of the patient group studied] had accessed palliative care services. **Abstract:** <https://goo.gl/MZfRNC>

N.B. Additional articles on palliative care and patients living with chronic obstructive pulmonary disease are noted in the 2 January 2017 issue of Media Watch (#493, p.9).

Palliative care in Africa: A scoping review from 2005–2016

LANCET ONCOLOGY, 2017;18(9):e522-e531. Since the last comprehensive review on the development of national palliative care (PC) in Africa was undertaken 12 years ago, in 2005, the authors did a scoping review of peer-reviewed, published articles on PC development between 2005–16 for each African country. The scoping review was conducted by assessing the medical literature and including local expert recommendations of suggested articles. The authors did a basic quality assessment of the articles using the journals’ impact factor, journal quartile, and the number of citations as suitable metrics for quality consideration. Articles published in English, Spanish, Portuguese, and French that mentioned at least one dimension of WHO’s PC public health strategy (implementation of services, education, policies, or medicine availability) and vitality (activity by professionals or advocates) were included. Of the 518 articles found, 49 met the inclusion criteria. Information on 26 (48%) of 54 African countries was found. Most services were concentrated in Kenya, South Africa, and Uganda, and 14 (26%) countries showed an increase in

Commentary

Palliative care in chronic obstructive pulmonary disease

THE LANCET | Online – 2 September 2017 – Recognition of the limits of curative treatment and acceptance of palliative care (PC) is hard for clinicians, patients, and their families, but is an important and often neglected part of clinical practice, particularly beyond oncology. For patients with cancer in many high-income countries, PC is a well researched and funded component of care, but for those dying from other diseases, its place is less accepted. For many in lower and middle income countries, there is simply no access to PC at all, which forms the focus of a Lancet Commission to be published in October, ahead of World Hospice & Palliative Care Day 14 October. The place of PC, and access to it, demands more attention worldwide. <https://goo.gl/ixnz3a>



Cont.

services during this timeframe. Stand-alone PC policies exist in Malawi, Mozambique, Rwanda, Swaziland, Tanzania, and Zimbabwe. Postgraduate diplomas in PC are available in Kenya, South Africa, Uganda, and Tanzania. Restricted access to opioids, prescriber restriction laws, and a low prevalence of morphine use remain common barriers to adequate PC provision. Although information on PC is unevenly distributed, the available information showed an increased development of PC services in a subset of African countries. Despite this growth, however, there is still minimal to no identified PC development in most African countries. **Summary:** <https://goo.gl/fFh7Ht>

Noted in Media Watch 10 July 2017 (#520, p.12):

- *JOURNAL OF GLOBAL ONCOLOGY* | Online – 30 June 2017 – ‘**Palliative care development in Africa: Lessons from Uganda and Kenya.**’ Despite increased access to palliative care (PC) in Africa, there remains substantial unmet need. The authors examined the impact of approaches to promoting the development of PC in Uganda and Kenya, and considered how these and other strategies could be applied more broadly. Both countries have implemented strategies across all five domains [i.e., education and training, access to opioids, public and professional attitudes, integration into national health systems, and research] to develop PC. In both countries, successes in these endeavors seem to be related to efforts to integrate PC into the national health system and educational curricula, the training of health care providers in opioid treatment, and the inclusion of community providers in PC planning and implementation. Research in PC is the least well-developed domain in both countries. A multidimensional approach to development of PC across all domains, with concerted action at the policy, provider, and community level, can improve access to PC in African countries. **Abstract:** <https://goo.gl/RP8FWv>

Trend analysis of end-of-life care between hospice and non-hospice groups of cancer patients in Taiwan for 2002–2011

MEDICINE, 2017;96(34):e7825. In this was a population-based cohort study of all cancer patients who died in Taiwan between 1 January 2002 and 31 December 2011, utilization of hospice service doubled from 10.5% to 21.5% over the study period. Of 12,682 patients identified as having advanced cancer, 7,975 (62.88%) were found to have 1 or more quality indicators of poor end-of-life cancer care. After adjustments, those receiving hospice care had a significant reduction in incidence of chemotherapy in the last 14 days of life as well as intensive care unit admission and cardiopulmonary resuscitation in the last month of life. **Full text:** <https://goo.gl/ajL2ix>

N.B. Additional articles on palliative and end-of-life care in Taiwan are noted in the 3 July 2017 issue of Media Watch (#519, pp.4-5).

Practicing medicine at the end of life: Use clear language

NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE | Online – Accessed 29 August 2017 – Up to thirty years ago, in The Netherlands the word ‘stervensbegeleiding’ [literally, dying-guidance] was used to refer to care for people in the last days of life. After Cicely Saunders had developed a multidisciplinary and multidimensional approach for care for the dying, the wording changed, until the word ‘palliative care’ (PC) was adopted. This care gradually developed from care for the dying to care for all people with life-threatening illness, as illustrated in the WHO definition. This shift in focus of care raises the question of when PC starts. The surprise question is regarded as a useful tool for marking this shift in focus of care. However, answering the surprise question does not inform us about PC needs. Nevertheless, when people enter the dying phase, a fundamental change in the nature of care is needed. The word ‘stervensbegeleiding’ marks this change of care. **Abstract:** <https://goo.gl/EkyoiB>

N.B. Dutch language article. Additional articles on the “surprise question” for predicting death in seriously ill patients are noted in the 7 August 2017 and the 10 April 2017 issues of Media Watch (#524, p.4 & #507, pp.10-11, respectively).

End-of-life care in England & Scotland

Comparing routine inpatient data and death records as a means of identifying children and young people with life-limiting conditions

PALLIATIVE MEDICINE | Online – 29 August 2017 – Using death record data alone to identify children and young people with life-limiting condition – and therefore those who would require palliative care services – would underestimate the numbers. This underestimation varies by age, deprivation, ethnicity and diagnostic group. In England, 16,642 (57%) non-neonatal cohort members had a life-limiting condition recorded as the underlying cause of death; 3,364 (12%) had a life-limiting condition-related condition recorded as the underlying cause and 3,435 (12%) had life-limiting conditions recorded only among contributing causes. In all, 5,651 (19%) non-neonates and 3,443 (41%) neonates had no indication of a life-limiting condition recorded in their death records. Similar results were seen in Scotland (overall, 16% had no indication of life-limiting conditions). In both cohorts, the recording of life-limiting condition was highest among those with haematology or oncology diagnoses and lowest for genitourinary and gastrointestinal diagnoses. **Full text:** <https://goo.gl/cUfXJX>

How long do I have? Observational study on communication about life expectancy with advanced cancer patients

PATIENT EDUCATION & COUNSELING, 2017;100(10):1820-1827. Life expectancy was addressed in 19 of 62 of consultations. In all cases, patients took the initiative, most often through direct questions. Estimates were provided in 12 consultations in various formats: the likelihood of experiencing a significant event, point estimates or general time scales of “months to years,” often with an emphasis on the “years.” The indeterminacy of estimates was consistently stressed. Also their potential inadequacy was regularly addressed, often by describing beneficial prognostic predictors for the specific patient. Oncologists did not address the reliability or precision of estimates. **Abstract:** <https://goo.gl/NSfu1e>

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

Repeal of the Affordable Care Act will negatively impact children at end of life

PEDIATRICS | Online – 30 August 2017 – Unfortunately, hospice care is drastically underutilized by children and adolescents at the end of life (EoL). Annually, more than three-fourths of the over 55,000 pediatric deaths take place in a hospital setting without hospice care involvement. Comprehensive hospice services for children offer an opportunity for family-centered care with prominent symptom management at the EoL. Although the majority of pediatric deaths are due to unintentional injury, it is estimated that nearly 17,000 deaths each year are due to chronic, complex conditions, and the majority of these children are enrolled in Medicaid because of their disability status, severity of disease, or overall functional status. Although a small proportion of the pediatric population (an estimated 0.4%-0.7% or 320,000-560,000 in total), children with medical complexity account for 15% to 33% of all pediatric health care spending and nearly 60% to 67% are enrolled in Medicaid. Before the Affordable Care Act, children enrolled in Medicaid and their families had to choose between continuing curative therapies or receiving hospice care services. **Abstract:** <https://goo.gl/HP1vqb>

American Academy of Pediatrics

Guidance on forgoing life-sustaining medical treatment

PEDIATRICS | Online – 28 August 2017 – Pediatric health care is practiced with the goal of promoting the best interests of the child. Treatment generally is rendered under a presumption in favor of sustaining life. However, in some circumstances, the balance of benefits and burdens to the child leads to an assessment that forgoing life-sustaining medical treatment (LSMT) is ethically supportable or advisable. Parents

Cont.

are given wide latitude in decision-making concerning end-of-life care for their children in most situations. Collaborative decision-making around LSMT is improved by thorough communication among all stakeholders, including medical staff, the family, and the patient, when possible, throughout the evolving course of the patient's illness. Clear communication of overall goals of care is advised to promote agreed-on plans, including resuscitation status. Perceived disagreement among the team of professionals may be stressful to families. At the same time, understanding the range of professional opinions behind treatment recommendations is critical to informing family decision-making. Input from specialists in palliative care, ethics, pastoral care, and other disciplines enhances support for families and medical staff when decisions to forgo LSMT are being considered. Understanding specific applicability of institutional, regional, state, and national regulations related to forgoing LSMT is important to practice ethically within existing legal frameworks. This guidance represents an update of the 1994 statement from the American Academy of Pediatrics on forgoing LSMT. **Full text:** <https://goo.gl/G6wxJH>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *HEALTHCARE MANAGEMENT FORUM*, 2017;30(5):262-265. **'Becoming dead: Two soliditudes?'** The moral divide between proponents and opponents of medical assistance in dying is wide and can be ascribed to a number of dichotomous beliefs. This article addresses a particular and less commonly described platform for the divide: human acquiescence to physical decline and death as an important stage of life, versus presumptive human mastery over the timing and manner of some peoples' death. Practical ideas are then offered for health systems that wish to bridge the divide, to provide both robust palliative end-of-life care and medical assistance in dying programs for their patients, while keeping health workers whole. **Abstract:** <https://goo.gl/BgDKZL>
- *JOURNAL FOR NURSE PRACTITIONERS* | Online – 28 August 2017 – **'Medical Assistance in Dying in Canada: Focus on rural communities.'** The 2015 *Carter v Canada* (Attorney General) case radically changed end-of-life care in Canada. This groundbreaking decision legalized physician-assisted suicide for competent adults who meet certain clinical criteria and who consent to their termination of life. The federal government then passed its legislative response, Bill C-14, to change the Criminal Code and legalize medical assistance in dying. Since Bill C-14 was enacted, the health care community has struggled to ensure that its implementation occurs in a legally compliant, patient-centered manner. This article focuses on the challenges of this new law for nurse practitioners, especially those in rural and remote communities. **Abstract:** <https://goo.gl/gg8bzP>
- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 29 August 2017 – **'Reasons to reject physician assisted suicide/physician aid in dying.'** Oncologists who care for persons with advanced, terminal cancer and who practice in jurisdictions where PAS/physician aid in dying (PAS/PAD) is legal now face individual decisions whether to endorse and/or participate in the practice. This editorial distills the arguments against PAS/PAD and the adverse implications it has for oncology professionals and persons with advanced, terminal cancer. First, the authors acknowledge the progress that has been made in end-of-life care in recent decades. Second, they focus on the reality that PAS/PAD is much less about physical pain and suffering than it is about the desire to have the control to end one's life. Third, the authors consider the unintended or unforeseen consequences of legalizing PAS/PAD, including decreased physician professionalism, the possibility of error, a diminished physician-patient relationship, and a slippery slope toward the practice of euthanasia. **Full text:** <https://goo.gl/9Ny3J5>
- *NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE* | Online – Accessed 30 August 2017 – **'Organ donation following physician-hastened death at home.'** Patients considering physician-hastened death (PHD) increasingly express a wish to donate organs after death. This fairly unique proposition stems from patients' desire to do something good with (parts of) the same diseased body that has prompted them to request physician-hastened death. The authors describe a patient with amyotrophic lateral sclerosis who expressed this wish. In March 2017 a national guideline on 'Organ donation following physician-hastened death' (ODP) was presented to the Minister of Health, Welfare & Sport of

Cont.

The Netherlands. From the development of this guideline it emerged that, for PHD patients, being forced to experience their final conscious moments in hospital – in order to facilitate organ donation – was a key reason for not choosing ODP. Together with an anaesthesiologist-intensivist, the GP of the ALS patient developed a domestic ODP, thereby overcoming the hurdle of experiencing death in hospital and maintaining the possible option of organ donation. The applied solution is an “anaesthesia bridge” which separates the experience of farewells, and losing consciousness under pre-medication at home, from biological death and organ donation in hospital. **Abstract:** <https://goo.gl/wwSmel>

N.B. Dutch language article.

- **PALLIATIVE MEDICINE** | Online – 29 August 2017 – ‘**Involvement of palliative care in euthanasia practice in a context of legalized euthanasia: A population-based mortality follow-back study.**’ In the international debate about assisted dying, it is commonly stated that euthanasia is incompatible with palliative care (PC). In Belgium, where euthanasia was legalized in 2002, the Federation for Palliative Care Flanders has endorsed the viewpoint that euthanasia can be embedded in PC. In Flanders, in a context of legalized euthanasia, euthanasia and PC do not seem to be contradictory practices. A substantial proportion of people who make a euthanasia request are seen by PC services, and for a majority of these, the request is granted. **Abstract:** <https://goo.gl/gt3YBN>
- **SOUTHERN MEDICAL JOURNAL**, 2017;110(9):563-568. ‘**Discussing advance care planning and directives in the general population.**’ The concept of end-of-life planning, along with medical and legal issues, has been discussed and has evolved over several years. The [U.S.] 1990 Patient Self-Determination Act and individual states’ department of health advance directive forms helped overcome past problems. Patients with terminal and chronic illness are now able to have their wishes recognized for their future care. Any healthy individual’s decision during an advance care planning (ACP) discussion can be adversely affected by various factors; however, multiple barriers – religion, culture, education, and family dynamics – can influence the process. Healthcare professionals’ reluctance to initiate the conversation may result from limited training during medical school and residency programs. These limitations hinder both the initiation and productiveness of an ACP conversation. The authors explore ACP issues to provide guidance to healthcare professionals on how best to address this planning process with a healthy adult. **Abstract:** <https://goo.gl/1QVW4T>

[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.

Media Watch: Online

International



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

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

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

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

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

Asia

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

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

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLqxy2>
[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>
[Scroll down to 'Additional Resources']

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

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>
[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W>
[Scroll down to International Palliative Care Resource Center – IPCRC.NET]

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

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

Barry R. Ashpole
Guelph, Ontario CANADA

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