

Media Watch...

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

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The illness experience: Scroll down to [Specialist Publications](#) and ‘Empathy, sympathy and compassion in healthcare: Is there a problem? Is there a difference? Does it matter?’ (p.12), in *Journal of the Royal Society of Medicine*.

Canada

Most Canadians who request assisted death won't get it – and some won't get palliative care, either

ONTARIO | TVO – 15 December 2016 – According to a report released by the Canadian Society of Palliative Care Physicians (CSPCP) in November,¹ only one of every six patients who ask for medically assisted death will be approved. Most of the 62,400 people projected to request it in 2017 will receive PC instead. But Canada is already having difficulty providing PC to those who need it, even without factoring in the surge in patients asking for medically assisted death. Just 30% of the 260,000 Canadians who die each year have access to PC. And many ... are given access only a few days or weeks before they die. In a report published this year, Health Quality Ontario said this province does no better than the rest of the country.² Most Ontarians die in hospital, and the majority don't access PC until their last two months of life. In order to meet the needs of those seeking medically assisted death in the next year, Ontario would have to double the number of practising PC specialists. Canada could look to Belgium for some pointers. Before 2002, when physician-assisted death was legalized, the Belgian government doubled spending on PC, and funding has increased more than 10% every year since. Its decision to boost support was based not only on the merits of PC, but also on the belief that assisted death would be unethical if it were carried out because of a lack of access. In Canada, federal health minister Jane Philpott plans to inject \$3 billion into the next budget to help advance both home and PC access for Canadians. But David Henderson, president of the CSPCP, says that's not enough. "Prime Minister Justin Trudeau and Health Minister Dr. Jane Philpott must do more," he said in a statement in November. The government, he added, has also failed to propose an implementation plan or make a clear commitment to universal access. And now that Canadians are guaranteed the right to medical assistance in dying, ensuring universal access to PC is essential. <https://goo.gl/vU5WtU>

1. 'How to improve palliative care in Canada: A call to action for federal, provincial, territorial, regional and local decision makers,' Canadian Society of Palliative Care Physicians, November 2016. [Noted in Media Watch 7 November 2016, #486 (p.2)] <https://goo.gl/DiBjDx>
2. 'Palliative Care at the End of Life,' Health Quality Ontario, June 2016. [Noted in Media Watch 4 July 2016, #469 (p.2)] <http://goo.gl/GW0Xh9>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CATHOLIC CULTURE* | Online – 14 December 2016 – ‘**Canadian bishops take different stands on sacraments for Catholics planning assisted suicide.**’ Two groups of Canadian Catholic bishops have issued instructions for pastors regarding the pastoral care of people planning assisted suicide. One group of bishops tells priests that Catholics planning suicide cannot receive the sacraments; the other group leaves that question open. <https://goo.gl/VzUjz7>
- CBC NEWS | Online – 13 December 2016 – ‘**Government launches promised review of issues left out of assisted dying law.**’ The federal government has initiated the promised review of its restrictive new law on medically assisted dying to determine if it should be expanded to include Canadians suffering strictly from mental illnesses, mature minors, and those with competence eroding conditions who want to make advance requests. It has engaged the Council of Canadian Academies to conduct independent reviews on each group and report back by December 2018. <https://goo.gl/wMI9NG>
- *THE GLOBE & MAIL* | Online – 13 December 2016 – ‘**Hospitals have no right to opt out of assisted dying.**’ Institutions do not have a conscience. Institutions do not have rights. People do. Yet, as provinces fashion regulations to conform to Canada’s new federal law on assisted death, they are consistently putting the concerns of hospitals (and other institutions) ahead of those of providers and patients. Faith-based institutions are routinely opting out of providing assisted death and, in many jurisdictions, there is a disturbing level of secrecy about which institutions provide assisted death and even how many patients have opted for hastened death. These approaches may well be outright unconstitutional; at best, they offend the spirit of the law and the principles of medicare. <https://goo.gl/FUBe2u>
- ALBERTA | *The Edmonton Journal* – 12 December 2016 – ‘**Demand for medically assisted death continues to rise in Alberta.**’ Sixty Albertans have received medical aid to end their lives this year, as demand for the service continues to grow across much the province. New statistics ... by Alberta Health Services show the number of assisted deaths has essentially doubled in the past two months, a trend that has confounded health leaders. Instead of tapering off following an initial surge of interest, demand appears to have grown stronger through the fall and into the start of the holiday season — months after new federal legislation came into effect. <https://goo.gl/6u9qTP>
- ALBERTA | *The Edmonton Sun* – 11 December 2016 – ‘**Alberta nurse practitioners authorized to provide medical assistance in dying.**’ Nurse practitioners in Alberta have been given provincial cabinet approval to provide medical assistance in dying. “Albertans who have a relationship with a nurse practitioner as their primary care provider now have more access to medical assistance in dying,” said Jerry Macdonald, said president of the College and Association of Registered Nurses of Alberta. “Nurse practitioners provide primary health care both as independent practitioners and as members of health care teams. The new standards of practice ensure that nurse practitioners can provide medical assistance in dying if required by their patients.” <https://goo.gl/d4Q1kE>

Specialist Publications

‘**Conscientious objection and “effective referral”**’ (p.14), in *Cambridge Quarterly of Healthcare Ethics*.



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>

U.S.A.

More prisoners die of old age behind bars

KAISER HEALTH NEWS | Online – 15 December 2016 – As the number of older prisoners soars, more inmates are dying in prison of diseases that afflict the elderly, new data from the Department of Justice show.¹ A total of 3,483 inmates died in state prisons and 444 in federal prisons in 2014, the highest numbers on record since the bureau started counting in 2001... In addition, 1,053 inmates died in local jails, where suicide is on the rise. The U.S. has the world's largest prison population, with over 2 million people behind bars. While that population has been shrinking in recent years, deaths in custody have climbed steadily. The deaths reflect a dramatic shift in the prison population: The number of federal and state prisoners age 55 or older reached over 151,000 in 2014, a growth of 250% since 1999. As this population grows, prisons have begun to serve as nursing homes

1. 'Mortality in State Prisons, 2001-2014: Statistical Tables,' Bureau of Justice Statistics, U.S. Department of Justice, December 2016. <https://goo.gl/DxZiV5>

America's elusive living wage meets the profits of dying

FORBES | Online – 14 December 2016 – Earning a living wage in America is among the urgent challenges and passionate causes of our time. How ironic, then, that the dying wage is so much better. The wages of death are excellent. Consider how most people in this country die. Overwhelmingly, we die of chronic diseases that are reliably preventable by means long at our disposal. We die of diabetes and its complications, we die of heart disease, cancer, pulmonary diseases and stroke. And because these are, indeed, chronic diseases – they do worse than kill us prematurely. They afflict us first with disability, inconvenience and a diminished quality of life. Before ever taking years from our lives, chronic diseases siphon away life from our years. The wages of death I have in mind are by no means limited to the profitable responses to all of this morbidity, but those are certainly included. We talk a lot, maybe now more than ever with a repeal of the Affordable Care Act brewing, about the costs of healthcare. But what is cost for some is cash flow for others. We doctors mostly do all right, in part due to the abun-

and hospice wards caring for the sickest patients. The majority of state prisoners who died in 2014 were 55 years or older, and 87% of state prisoners died of illnesses, according to the report. The most common illnesses were cancer, heart disease and liver failure. These deaths point to how dramatically prisoners' health care needs are changing. <https://goo.gl/b3aUMk>



Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of the articles, reports, etc., noted in past issues of the weekly report is available at: <http://goo.gl/ZpEJyQ>

dant pathology that keeps us all busy. So, too, our many comrades in the clinical enterprise: nurses, PAs and technicians of every description. But, as ever, the individuals with sleeves rolled up and soiled hands are never first in line when the really big checks are being handed out. The big winners here are executives at major pharmaceutical and healthcare technology companies, and to a lesser extent, top brass in hospital administration. Yes, healthcare is costly – but, it is also very profitable. Were everyone suddenly to turn healthy, it would be very bad news in certain quarters, Wall Street among them. <https://goo.gl/AhnbTU>

Specialist Publications

'Palliative care for patients with advanced illness: A changing policy landscape' (p.7), in *American Journal of Managed Care*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLORADO | *The Denver Post* – 16 December 2016 – ‘**Colorado medical-aid-in-dying law signed by Governor John Hickenlooper, takes effect immediately.**’ Governor John Hickenlooper ... signed into law a voter-passed initiative to allow terminally ill adults to end their lives with prescribed medication. Proposition 106, known as ‘End of Life Options,’ took effect the moment Hickenlooper penned his name. Hickenlooper – one of five Colorado elected officials to support the measure publicly – said the law gives people a critical choice. Two thirds of Colorado voters approved the measure in November. <https://goo.gl/giMJDW>

International

End-of-life care in Australia

A good death

AUSTRALIA (New South Wales) | *The Weekend Australian* – 17 December 2016 – For 20 years Yong Nie dodged Australian authorities by lying low, staying out of trouble, earning cash in hand through odd jobs, sleeping rough and keeping to himself. But when he developed an aggressive cancer, the game was up. Gaunt, jaundiced, his once dark hair streaked grey, the 68-year-old illegal immigrant turned up at the emergency department of Sydney’s St Vincent’s Hospital doubled in pain and fearing deportation. But instead of being thrown out, locked up and shipped off, he was welcomed by palliative care staff who took him in as one of our own. The good death at the heart of this story confirms the generosity of ordinary people performing exceptional acts of compassion without triumphalism or reward because this is what they do every day. Few of those who crossed Nie’s path during the two months he spent at the inner-city hospital founded by the Sisters of Charity will forget him. They couldn’t cure his disease-ridden body but they worked tirelessly to heal a terrible burden in his soul. Those drawn to fulfil his dying wish came from different faiths and countries. There were doctors, nurses and social workers employed in this Catholic health service; monks and volunteers from the Nan Tien Buddhist temple near Wollongong; a Chinese community cancer support agency and Australian Embassy officials in Beijing. Racing against death’s advance, they embraced this fringe dweller who had fallen foul of officialdom with gracious gestures that celebrate the humanity of frontline carers while reminding us how lucky we are to live in a country where goodness thrives. <https://goo.gl/v5gESc>

Annual report on end-of-life care in Wales sees real improvements

U.K. (Wales) | *Care Appointments* – 16 December 2016 – Increasing numbers of people who wish to spend their final days at home have been supported to do so, according to the latest Welsh Government annual report into the care of terminally ill people.¹ An annual investment of over £1 million in the Hospice-at-Home programme has enabled more people who are terminally ill to be rapidly discharged and die at home if that is their wish. Where this process is in place, 99% of patients who wished to die at home were able to do so. Care is improving in hospital too, with more specialist care available around the clock. Across Wales, processes and procedures have been put in place supporting clinical nurse specialist teams to work seven days a week. Consultants in palliative medicine are now available on call to provide 24/7 specialist advice and support for children and young people and adults. Working in regional teams, they can access patient information to make decisions about the care of patients with complex needs. Healthcare professionals who care for patients for whom terminal illness may be sudden and unexpected can now receive extra communications training around end-of-life care. <https://goo.gl/ZRI9uE>

1. ‘Together for Health: End-of-life care annual report 2016,’ National Health Service Wales, December 2016. <https://goo.gl/vYHCP6>

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

New report explores South Asian communities views on end-of-life care and treatment

U.K. | *Asian Image* – 14 December 2016 – A new report has explored the views of people from South Asian communities about end-of-life care (EOLC)...¹ The report details findings and recommendations from a pioneering project aimed at engaging the South Asian community in planning ahead for EOLC and treatment. The project was part of Compassion in 'Dying's My Life, My Decision' programme, run in partnership with seven local Age UK partners, which aimed to engage people aged over 50 to think about and plan their care in advance, helping to ensure they have the EOLC that's right for them. The report identifies key findings from the project and sets out recommendations for health and social care providers and other organisations working with South Asian communities, in order to more effectively engage individuals and groups in planning ahead for EOLC and treatment. These include a need to: 1) Provide written information in English and Urdu; 2) Share learning from other communities and groups; 3) Be aware of what language the group prefers to communicate in; 4) Build a social media strategy into the workshops; and, 5) Focus on building trust and a safe space for people to talk; 6) Provide written information on the legal position around post-mortem examinations and organ donation. <https://goo.gl/jTzttm>

1. 'Tea, Talk and Samosas: Planning ahead for the end of life with the South Asian community,' Compassion in Dying, October 2016. <https://goo.gl/bKN0iw>

Noted in Media Watch 14 October 2013, #327 (p.8):

- *PALLIATIVE MEDICINE* | Online – 9 October 2013 – '**Dying at home: A qualitative study of the perspectives of older South Asians living in the U.K.**' Two key themes were identified: "reconsidering the homeland" draws on the notion of "diaspora" to help understand why, for many study participants, the physical place of death was perceived as less important than the opportunity to carry out cultural and religious practices surrounding death; and, "home as a haven" describes participants' accounts of how their home is a place in which it is possible to perform various cultural and religious rituals. <https://goo.gl/mIVC0u>

Dying and death in England

Hospitals fail too often to investigate deaths, National Health Service watchdog finds

U.K. (England) | *The Guardian* – 13 December 2016 – Hospitals are failing to investigate far too many deaths and frequently ignore and exclude relatives of patients who have died, a major National Health Service inquiry has found. The health service's failure to properly look into deaths is "a system-wide problem" that means hospitals are not learning from their mistakes and thus stopping other tragedies from occurring, its report says.¹ The Care Quality Commission (CQC) report, ordered by health secretary Jeremy Hunt, is scathing about hospitals' shoddy and insensitive treatment of bereaved relatives' requests for information and to be involved in an inquiry. The CQC, the care watchdog for England, intends to overhaul how hospitals look into unexpected patient deaths or

deaths owing to mistakes by staff. Investigations in future should be more thorough, more open and involve families much better, it promised. The review team based their findings on assessing how 12 NHS trusts responded to unexpected or unusual patient deaths or deaths where errors had occurred, discussion with more than 100 families and a survey of all NHS trusts in England. <https://goo.gl/W8on0l>

Last year 495,309 deaths were registered in England. Of these, 232,442 (47%) people died in hospital with even more dying while receiving services provided by NHS trusts as an outpatient or from community services provided by the trust. **Source:** CQC

1. 'Learning, candour and accountability: Full report,' Care Quality Commission, December 2016. <https://goo.gl/8xWUpP>

Cont.

Related

- U.K. (England) | *The Daily Mail* – 12 December 2016 – ‘**Ambulance crews grant final wishes to the dying.**’ Ambulances are taking terminally ill patients to special places of their choice under an National Health Service initiative. The End-of-Life Transport scheme gives patients the option to be transported by ambulance, along with a specially-trained crew, to their preferred place to die. Usually that involves taking people from hospital to their home, where they can spend their final days surrounded by loved ones. <https://goo.gl/ykQSt3>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | *The Conversation* – 14 December 2016 – ‘**Euthanasia and palliative sedation are distinct concepts – intent matters.**’ Some doctors suggest that, under the double effect doctrine, palliative sedation (PS) can be applied more liberally. The relief of pain can actually result in the death of a patient, which means PS can cover many of the cases of individuals seeking euthanasia. The argument then is, because PS does the same work as the euthanasia law is intended to cover, we needn’t create a law to legalise euthanasia; we need only clarify existing law on double effect and PS. I’ll call this the “minimalist thesis.” But there is a strong argument to suggest the minimalist thesis is untenable. Euthanasia and PS are categorically distinct. This is because the intent – which is the operative word when it comes to moral philosophy and to legal principles – of doctors in each of the interventions is different. In PS, doctors administer pain relief with the primary intent of relieving pain. In the case of active euthanasia, doctors administer barbiturates with the primary intent of ending the patient’s life. <https://goo.gl/78GHvJ>
- AUSTRALIA (Victoria) | ABC News (Melbourne) – 5 December 2016 – ‘**Assisted dying: Victorian government to introduce bill in second half of 2017.**’ Victoria could become the first state in Australia to legalise assisted dying for the terminally ill, with a government bill to be introduced to the Parliament next year. A ministerial advisory panel made up of clinical, legal, consumer, health administration and palliative care experts will be established to help draft a “safe and compassionate” legislative framework for assisted dying. MPs will be granted a conscience vote, which means there is no guarantee the bill will pass through the lower and upper houses of the Parliament. Premier Daniel Andrews said the legislation would reflect the recommendations of a cross-party parliamentary committee that delivered a ground-breaking report in June calling for doctor-assisted dying to be legalised with strong safeguards. <https://goo.gl/P6iXRI>

[Specialist Publications](#)

Predatory publishing: An emerging threat to the medical literature

ACADEMIC MEDICINE | Online – 6 December 2016 – The quality of medical literature is increasingly threatened by irresponsible publishing, leading to rising retraction rates, irreproducible results, and a flood of inconsequential publications that distract readers from more meaningful scholarship. “Predatory publishers” offer rapid publication with loose peer review, exploiting a system in which faculty seek longer bibliographies to achieve academic promotion. In this Commentary, the authors highlight some of the evidence that this problem exists and suggest actions to address it. Recommendations for protecting the medical literature include: 1) Preventing predatory journals from being indexed by the [U.S.] National Library of Medicine; 2) Encouraging academic promotions committees to ensure that they prioritize value over volume of publications and that faculty understand that priority; 3) Excluding publications from predatory journals on *curricula vitae* and requiring that retractions are included; 4) Developing sanctions for repeated retractions or duplicate publications; and, 5) Convening an expert panel to better elucidate this problem and determine strategies to combat it. <https://goo.gl/X3Sj29>

N.B. Additional articles on predatory journals are noted in Media Watch, e.g., 5 December 2016, #490 (p.2); 5 September 2016, #478 (p.14); 30 May 2016, #464 (p.11); and, 11 April 2016, #457 (p.7).

The influence of palliative care consultation on health-care resource utilization during the last two months of life: Report from an integrated palliative care program and review of the literature

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 17 December 2016 – The authors reviewed 104 consecutive deaths of veterans receiving care in the Dayton Veterans Affairs Medical Center from 10 October 2015 to 11 April 2016. Of 102 consecutive veteran deaths, palliative care consultation (PCC) was associated with a lower number of ICU days during the last two months of life. For 96 veterans with PCC, the frequency of emergency department visits and acute care hospitalizations, as well as the number of ICU and hospital days, were all significantly less after PCC compared to before PCC during the last two months of life. <https://goo.gl/yoOe8M>

Families' perception of end-of-life care for patients with serious illness

AMERICAN JOURNAL OF KIDNEY DISEASES | Online – 5 December 2016 – During the last half century, many of the advances in medical technology, clinical medicine, and health care delivery that have helped maintain health and extend life may also have moved us further away from the “good death” that many of us hope for. This may be especially true for patients with advanced kidney disease. The now widespread availability of maintenance dialysis therapy means that many of these patients face a unique and challenging set of treatment decisions, including whether and when to initiate and eventually discontinue dialysis treatments. <https://goo.gl/tBch9k>

Noted in Media Watch 30 May 2016, #464 (p.13):

- *NEPHROLOGY DIALYSIS TRANSPLANTATION* | Online – 19 May 2016 – ‘**End-of-life care for people with chronic kidney disease: Cause of death, place of death and hospital costs.**’ The proportion of deaths at home [in the U.K.] was 10.7% in people with chronic kidney disease (CKD)... CKD was associated with an increase in hospital costs of £3,380 in the last 12 months of life, holding constant place of death, co-morbidities and other variables. Home death was associated with a reduction in hospital costs of £2,811 in the 12 months before death. <http://goo.gl/EtWjGv>

N.B. Additional articles on end-of-life care for people living with kidney disease are noted in Media Watch 14 March 2016, #453 (p.10).

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

Palliative care for patients with advanced illness: A changing policy landscape

AMERICAN JOURNAL OF MANAGED CARE | Online – 13 December 2016 – Every day, 10,000 Americans join the Social Security and Medicare rolls. Moreover, individuals 80 and older are the fastest growing demographic among older adults, with their ranks forecast to grow from 5.6 million in 2010 to more than 19 million by 2050.¹ The rising number of aging Americans creates a commensurate increase in the costs for healthcare. While they constitute only 24% of Medicare beneficiaries, seniors 80 and up account for more than 33% of Medicare expenditures; much of that spending stems from the prevalence of chronic diseases and high end-of-life (EOL) costs. In 2012, half of all individuals with new cancer diagnoses were Medicare beneficiaries, with that figure expected to rise over 10 years. Additionally, \$1 in every \$12 of Medicare fee-for-service spending was spent on cancer care in 2015. With the demographic shift underway, policy makers, payers, and providers have been exploring models of care that can offer better quality, improve the overall patient experience, and also reduce costs. In the 6 years since passage of the landmark and controversial Affordable Care Act, a variety of new approaches have emerged with this goal in mind, and a significant change has been the integration of palliative care. <https://goo.gl/aFIdAu>

Related

- *JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK*, 2016;14(12):1493-1494. ‘**Palliative care – the challenge of application.**’ Despite the growing recognition that the interdisciplinary team approach of palliative care can be extremely beneficial for patients with cancer and their families, barriers to implementation of the National Comprehensive Cancer Network Guidelines for Palliative remain, even among Network member institutions. <https://goo.gl/Clojq9>

A personal journey in Taiwan's hospice palliative care movement

BAOJ PALLIATIVE MEDICINE | Online – Accessed 15 December 2016 – Hospice palliative care started in Taiwan in 1990. Foundations of Christian, Catholic and Buddhist background and associations with medical, nursing and various social backgrounds joined in promotion of this modern humanistic medical care. Government organizations, especially the Ministry of Health & Welfare and the National Health Insurance (NHI) added policy momentum. Total subsidies for hospice care were provided by NHI. Hospice Palliative Care Act (a Natural Death Act) was enacted in 2000 and Patient Self-Determination Act passed in 2016. Clinical Buddhist Chaplaincy training program was started in 1998 and exported to Japan in 2013. A Taiwan Coma Scale was proposed for shortening of terminal suffering. Up to present, Taiwan has 57 hospice wards for the population of 23 millions. 93 hospitals provide hospice home care, 141 hospitals providing hospice combined care, and 155 hospitals providing community hospice care, covering almost all cities and counties. <https://goo.gl/YbAb6B>



N.B. Taiwan was ranked 6th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/nuPWII>

How do parents experience support after the death of their child?

BMC PEDIATRICS | Online – 7 December 2016 – Different types of support are provided to parents after the death of their child. Although increasing attention has been paid to supporting families after the loss of a child, one-fifth to slightly more than half of the parents in this study lacked some sort of support or experienced support that was not in line with their needs or wishes. According to the results of this study, support initiated by professional should always include listening to parents and asking them at key moments after their child's death whether they need (extra) support and what kind of support they would like to receive. Parents should also be asked specifically about the emotional support they receive from their family and their social network. When they lack this type of support, caregivers should explore with them how to reach out and receive more support. Furthermore, adequate communication skills and a respectful attitude are necessary in approaching the parents of a deceased child. Future study is necessary in which parents are contacted through hospitals or government registries of death in order to compare the responses of those who participate in support groups and those that do not. <https://goo.gl/9BxMlr>

Noted in Media Watch 6 June 2016, #465 (p.14):

- *CANCER* | Online – 31 May 2016 – '**Helping parents live with the hole in their heart: The role of health care providers and institutions in the bereaved parents' grief journeys.**' Bereaved parents [i.e., study participants] consistently identified the critical role played by medical staff and medical institutions throughout the grief journey. Key components of bereavement support identified by parents should serve to guide the actions of providers as well as provide a template for the development of a comprehensive bereavement program within an institution. <http://goo.gl/xlsPQa>
- *JOURNAL OF PEDIATRIC HEALTH CARE* | Online – 28 May 2016 – '**The development of a hospital-wide bereavement program: Ensuring bereavement care for all families of pediatric patients.**' The authors describe the development of a hospital-wide bereavement program at Boston Children's Hospital, where they conceptualize bereavement care as a preventive model of care. The authors identify the primary constructs of the program as education, guidance, and support and outline a template for use by other hospitals. <http://goo.gl/QPi9z8>

Cont.

Related

- *JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS*, 2016;14(11):99-105. 'Parents' and families' experiences of palliative and end-of-life neonatal care in neonatal settings: A systematic review protocol.' The overall objective of this systematic review is to identify, critically appraise and synthesize the parents' and families' experiences of palliative and end-of-life neonatal care at facilities/services globally. <https://goo.gl/jzHQLW>

What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large U.K. city

BMJ OPEN, 2016;6(12). For patients with advanced cancer, several randomised controlled trials have shown that access to palliative care (PC) at least 6 months before death can improve symptoms, reduce unplanned hospital admissions, minimise aggressive cancer treatments and enable patients to make choices about their end-of-life care (EOLC), including exercising the choice to die at home. This study shows that the current timing of referral to PC may limit the benefits to patients in terms of improvements in EOLC, particularly for older patients and patients with conditions other than cancer. Research is now urgently needed to better understand how the duration of PC reported here impacts on the quality of EOLC in order to develop and evaluate service-level interventions. <https://goo.gl/pUiStl>

No matter the species

American Veterinary Medical Association, hospice association release end-of-life care guidelines

JOURNAL OF THE AMERICAN VETERINARY MEDICAL ASSOCIATION | Online – 14 December 2016 – The American Animal Hospital Association and the International Association for Animal Hospice & Palliative Care have released guidelines on end-of-life care (EOLC) for pets. EOLC and decision-making “embody the critical final stage in a pet’s life and are as important and meaningful as the sum of the clinical care provided for all prior life stages,” according to the guidelines.

They provide practice teams with the framework and tools to develop a comprehensive, collaborative end-of-life plan and better recognize the needs of patients, clients, and team members during this difficult time. According to the guidelines: 1) EOLC and decision-making are medically, emotionally, and ethically challenging for everyone involved; 2) Studies have shown that 30% of pet owners will experience substantial grief following the loss of a pet, and 50% will question their decision following euthanasia; 3) Veterinary team members are at higher risk of compassion fatigue when they work with patients nearing their life’s end and their owners and are immersed in an environment of intense emotional and physical suffering, often of extended duration, with little group support; 4) The guidelines review the latest information to help staff address central issues and perform essential tasks to improve the quality of life of a pet who has entered the final life stage; and, 5) In addition, these guidelines define the role of each staff member so everyone on the practice team can work together to offer the best-quality medical care. <https://goo.gl/2OHQ1h>



N.B. The interesting parallel to be drawn between the practice and philosophy of hospice and palliative care and how end-of-life care for domestic animals has evolved in recent years has occasionally been highlighted in *Media Watch*, e.g., 3 October 2016, #482 (p.13) and 11 April 2016, 457 (p.14). **BRA**

Deactivation of left ventricular assist devices: Differing perspectives of cardiology and hospice/palliative medicine clinicians

JOURNAL OF CARDIAC FAILURE | Online – 5 December 2016 – The authors administered a 41-item survey ... to members of three cardiology and one hospice/palliative medicine (HPM) professional societies. Three domains emerged: 1) Left ventricular assist device (LVAD) as a life-sustaining therapy; 2) Complexities of the process of LVAD deactivation; and, 3) Legal and ethical considerations of LVAD deactivation. Most respondents (cardiology=92%; HPM=81%) believed that an LVAD is a life-sustaining treatment for patients with advanced heart failure; however, 60% of cardiology versus 2% of HPM clinicians believed a patient should be imminently dying in order to deactivate an LVAD. Additionally, 87% of cardiology versus 100% of HPM clinicians believed the cause of death following LVAD deactivation was from underlying disease, with 13% of cardiology clinicians considering it to be a form of euthanasia or physician-assisted suicide. Bridging the gaps and engaging in dialogue among these two specialties is a critical first step in creating a more cohesive approach to care for LVAD patients. <https://goo.gl/Dsa7eM>

Related

- *JOURNAL OF CARDIAC FAILURE* | Online – 9 December 2016 – ‘Palliative care in heart failure: Architects needed.’ Despite the development of new medications, monitoring capabilities, and device therapies, heart failure remains a disease of high morbidity and mortality. The role of palliative care (PC) in heart failure has gained increased attention in recent years, with an emphasis on providing patients with this complex syndrome an additional layer of support. This includes a focus on quality of life and relief from pain and other distressing symptoms. Expert and public opinion, as well as professional and policy organizations are increasingly calling for the expansion of PC into the care of patients with heart failure. <https://goo.gl/tc4vt5>

Is there a role for law in medical practice when withholding and withdrawing life-sustaining medical treatment? Empirical findings on attitudes of doctors

JOURNAL OF LAW & MEDICINE | Online – Accessed 12 December 2016 – The law regulates many aspects of decision-making around the withholding and withdrawing of life-sustaining medical treatment from adults who lack decision-making capacity and are approaching the end of their lives. For example, it governs whether an adult's advance directive is binding and applicable and, if not, who is authorised to make the treatment decision and the criteria that should guide the decision. Doctors who treat patients at the end of life should be aware of the prevailing law so they can practise within those legal parameters. However, the law in this field is complex and challenging for doctors to know and understand. Doctors will be prepared to invest time into learning about the law only if they believe the law is worth knowing and that practising medicine in a legally compliant way is a desirable goal. This article provides insight into doctors' attitudes about the role of law in medical practice in this field and argues education is required for doctors to reconceptualise knowledge of the law as constituting an integral component of their clinical expertise. <https://goo.gl/wh7u1W>

The knowledge and practice of doctors in relation to the law that governs withholding and withdrawing life-sustaining treatment from adults who lack capacity

JOURNAL OF LAW & MEDICINE | Online – Accessed 12 December 2016 – Law establishes a framework for making decisions about withholding and withdrawing life-sustaining treatment from adults who lack capacity. However, to what extent do doctors know and follow this law? This article reports on a three-year empirical study that sought to answer these questions. The research found doctors have significant legal knowledge gaps in this area. It also found that doctors do not attach significant weight to legal considerations in their decision-making. This article argues that law does have a role to play in end-of-life care. However, law reform is needed to make the law more accessible, medical education needs to be improved, and a change in attitude by doctors to medical law is required. <https://goo.gl/5B6Mst>



**Australian Centre for
Health Law Research**

Cont.

Noted in Media Watch, 14 November 2011, #227 (p.8):

- *JOURNAL OF LAW & MEDICINE*, 2011;18(4):773-797. **‘The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria).’** This is the final article in a series of three that examines the legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment from adults who lack capacity. <https://goo.gl/DvzonY>

N.B. Part 1 (New South Wales) and Part 2 (Queensland) noted in Media Watch 30 May 2011, #203 (p.8).
Journal contents page: <https://goo.gl/lhPj8h>

Health system advance care planning culture change for high-risk patients: The promise and challenges of engaging providers, patients, and families in systematic advance care planning

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 December 2016 – The success of a facilitator-based model for advance care planning (ACP) in La Crosse, Wisconsin, has inspired health systems to aim for widespread documentation of advance directives, but limited resources impair efforts to replicate this model. One promising strategy is the development of interactive, Internet-based tools that might increase access to individualized ACP at minimal cost. The authors describe their experiences in building a systematic, population-based ACP initiative focused on health system-wide deployment of an Internet-based tool as an adjunct to a facilitator-based model. With the sponsorship of their healthcare system’s population health leadership, the authors engaged a diverse group of clinical stakeholders as champions to design an Internet-based ACP tool and facilitate local practice change. Over 18 months, the project engaged two subspecialty clinics in a systematic ACP process and began work with a large primary care practice with a large Medicare Accountable Care Organization at-risk population. 807 people registered at the Internet site and 85% completed ACPs. Changing culture and systems to promote ACP requires a comprehensive vision with simultaneous, interconnected strategies targeting patient education, clinician training, electronic medical record documentation, and community awareness. <https://goo.gl/3wVqrR>

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 17 December 2016 – **‘The influence of hypothetical death scenarios on multidimensional end-of-life care preferences.’** Differences in end-of-life care (EOLC) preferences (e.g., location of death, use of life-sustaining treatments, openness to hastening death, etc) based on hypothetical death scenarios and associated physical and/or cognitive losses have yet to be investigated within the palliative care literature. Results [of this study] revealed significant differences in multidimensional care preferences between hypothetical death scenarios related to preferences for location of death (i.e., home vs medical facility) and preferences for life-prolonging treatment options. <https://goo.gl/OvSjIS>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 13 December 2016 – **‘Earlier goals-of-care discussions in hospitalized terminally ill patients and the quality of end-of-life care: A retrospective study.’** The results of this study underscore the importance of having a goals-of-care discussion (GOCD) as early as possible, particularly when a patient has been admitted with a terminal condition. Previous studies have demonstrated a link between GOCD and fewer aggressive measures at end of life, fewer in-hospital deaths and a greater use of hospice, and fewer ICU admissions and shorter ICU length of stay. <https://goo.gl/GoQjWF>
- *INTERNATIONAL JOURNAL OF EVIDENCE-BASED HEALTHCARE*, 2016;14(4):203. **‘Knowledge into practice: Improving advance care planning and palliative care for older people in Australia.’** The authors report results from a blended learning program (online modules and two face to face workshops approximately two months apart) delivered to clinical staff working in residential aged care facilities and community aged care services. The aim was to promote participation in advance care planning (ACP) discussions and palliative care (PC) case conferences with residents/clients. Almost half (47.3%) of residential and community (49.0%) aged care staff had a ACP discussion with new residents/clients and approximately two thirds of participants had ACP discussions with existing residents/clients... Completion of an advance care directive (32.4% vs 19.3%) or advance care plan (37.1% vs 21.6%) was significantly more likely to have been practiced by residential participants compared to their community counterparts. Residential care participants were also significantly more likely to report facilitating (33.6% vs 14.3%) a PC case conference or attending (28.8% vs 15.8%) a PC case conference than community staff. <https://goo.gl/3PsXgf>

Providing optimal palliative care for persons living with dementia: A comparison of physician perceptions in The Netherlands and the U.K.

JOURNAL OF PALLIATIVE MEDICINE | Online – 12 December 2016 – Physicians in The Netherlands and Northern Ireland (NI), U.K., prioritized the same domains of optimal palliative care (PC) for dementia and these match the priorities in the European Association for Palliative Care (EAPC) endorsed guidelines.¹ Respondents in both countries rated lack of education of professional teams and lack of awareness of the general public among the most important barriers to providing PC in dementia. NI respondents also identified access to specialist support as a barrier. The results indicate that there is a strong consensus among experts, elderly care physicians, and general practitioners across a variety of settings in Europe that person-centered care involving optimal communication and shared decision making is the top priority for delivering optimal PC in dementia. <https://goo.gl/4ZmG8g>

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

Related

- *GÉRIATRIE ET PSYCHOLOGIE NEUROPSYCHIATRIE DU VIEILLISSEMENT*, 2016;14(4):447-53. 'Palliative care for dementia patients.' Although symptoms of dementia and cancer patients are similar, palliative care is less frequently proposed for dementia patients. However, professionals and family members of demented patients strongly favor comfort care for end-stage dementia. To improve the patients' relief near the end of life, advance care planning with patients and their proxies should be encouraged. It should start as soon as possible so that the patient can still be actively involved and his preferences, values, needs and beliefs elicited. <https://goo.gl/abJomg>

N.B. French language article. Additional articles on end-of-life care for people living with dementia are noted in Media Watch, e.g., 12 December 2016, #491 (p.8); 5 December 2016, #490 (p.7); and, 17 October 2016, #483 (pp.9-10).

Empathy, sympathy and compassion in healthcare: Is there a problem? Is there a difference? Does it matter?

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE, 2016;109(12):446-452. Empathy, sympathy and compassion are defined and conceptualised in many different ways in the literature and the terms are used interchangeably in research reports and in everyday speech. This conceptual and semantic confusion has practical implications for clinical practice, research and medical education. Empathy, sympathy and compassion also share elements with other forms of pro-social behaviour such as generosity, kindness and patient-centredness. There is a need for conceptual clarity if doctors are to respond to the calls to provide more "compassionate care." This paper argues that there is currently a problem in the balance between scientific-technical and psychosocial elements of patient care. A broad model of empathy is suggested which could replace the vaguer concepts of sympathy and compassion and so enable improvements in patient care, psycho-social research and medical education. <https://goo.gl/E9byLi>

Noted in Media Watch 26 September 2016, #481 (pp.1-2):

- *PALLIATIVE MEDICINE* | Online – 17 August 2016 – 'Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences.' Sympathy was described as an unwanted, pity-based response to a distressing situation, characterized by a lack of understanding and self-preservation of the observer. [Noted in Media Watch 22 August 2016, #476 (p.14)] <http://goo.gl/7vHa89>

Help for hospice staff: Meaningful rituals

MEDSCAPE | Online – 13 December 2016 – Rituals are symbolic activities that can provide comfort, meaning and support, and relieve anxiety associated with uncertainties, such as those faced at the end of life. Rituals offer opportunities for shared experiences and can be an important part of the healing process. For clinicians who care for dying patients and their family members rituals can offer a way to channel their responses to the secondary traumatic stress of repeated exposure to suffering and death. Extensive models for staff support that include memorial services or public rituals exist nationally within hospices. However, these types of rituals may occur sporadically, perhaps only once yearly. <https://goo.gl/0xBrsk>

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

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 23 June 2016 – ‘**Personally meaningful rituals: A way to increase compassion and decrease burnout among hospice staff and volunteers.**’ Three hundred ninety hospice staff and volunteers from across 38 [U.S.] states completed an online survey. The majority of respondents used personally meaningful rituals after the death of their patients to help them cope (71%). <http://goo.gl/AoElto>

Literature review of best health and social care practices for individuals with intellectual disabilities encountering the end of life

NURSING & PALLIATIVE CARE, 2016;1(5);118-123. The authors analyzed thirty primary research articles, from which four emergent themes were identified: 1) End-of-life care (EOLC) approaches, policies and guidelines; 2) Challenges experienced by members of the health and social care team; 3) The importance, challenges and benefits of communication; and, 4) Examples of good practice including rounded EOLC that emphasises working collaboratively and inclusively with family and friends. Further, overall findings revealed that there was an absence of policies, procedures and guidelines governing these critical EOLC practices, including decision making processes. This means that committed members of the health and social care team working to engage with and support individuals with intellectual disabilities at the EOLC habitually underprepared as they lack appropriate communication skills, experience of dealing with death, relevant training and formal support. On top of this, the literature review indicated that there was inadequate collaborative, interagency and multi-professional working. This requires also the integration of the views of the individual with disabilities into models of care, using plain language when communicating with them, especially when breaking bad news that extends to their families and friends. Similarly, the provision of integrated services that respects and fosters autonomy of the dying person with intellectual disabilities. <https://goo.gl/GHeJug>

N.B. Click on ‘Download’ to access full text.

Noted in Media Watch 15 August 2016, #475 (p.12):

- *RESEARCH IN DEVELOPMENTAL DISABILITIES*, 2016;59(12):55-64. ‘**Physicians’ identification of the need for palliative care in people with intellectual disabilities.**’ Identification of people with intellectual disabilities (ID) in need for palliative care (PC) mostly results from a process in which multiple signals from different information sources converge and lead to a growing awareness. As a result, ID-physicians do not expect people to return to their prior level of health or functioning, but rather expect an irreversible decline leading to death. <http://goo.gl/0AuHy9>

Noted in Media Watch 28 March 2016, #455 (p.9):

- *BMC PALLIATIVE CARE* | Online – 24 March 2016 – ‘**Developing research priorities for palliative care of people with intellectual disabilities in Europe: A consultation process using nominal group technique.**’ The proposal of four major priority areas and a range of minor themes for future research in intellectual disability, death, dying and palliative care will help researchers to focus limited resources and research expertise on areas where it is most needed and support the building of collaborations. <http://goo.gl/fNxm6x>

N.B. Additional articles on palliative care for people living with intellectual disabilities are noted in Media Watch 1 August 2016, #473 (p.14), and 8 February 2016, #448 (p.12).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS*, 2017;26(1):32-43. ‘**Conscientious objection and “effective referral.”**’ What should the position be of health professionals who are expected to participate in actions that they believe are morally wrong? Professional responsibilities may clash with private conscience. Even referring a patient to someone else, when what is in question may be assisted suicide, or euthanasia, seems to involve some complicity. This is a live issue in Canada, but similar dilemmas occur elsewhere. Physicians and others should not be coerced into involvement of any kind in what they regard as wrong. Such coercion goes against the very principles of liberal democracy. Conscience matters. Reasonable accommodation should be given to those whose moral judgment may be at variance with prevailing professional norms. Moral questions should still be given weight within medicine, and disagreements respected. Dedication to the promotion of human welfare should be paramount, but it should be recognized that there may be different visions of what such welfare consists of. <https://goo.gl/CSzHq7>

N.B. This issue of the *Cambridge Quarterly of Healthcare Ethics* includes several articles on conscientious objection. Journal contents page: <https://goo.gl/YRIVv>

Media Watch: Editorial Practice

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

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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.



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Media Watch: Online

International

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

Link updated 12.12.2016

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 Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

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

Canada

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

Europe

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

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1l9K>

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

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