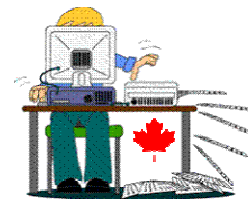


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Proactive approach to improving the quality of end-of-life care: Scroll down to [Specialist Publications](#) and 'Integrated palliative care is about professional networking rather than standardisation of care: A qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries' (p.14), in *Palliative Medicine*.

Canada

How lack of MD house calls keeps people from dying at home – where they want to die

ONTARIO | *The Ottawa Citizen* – 15 February 2018 – Dr. Peter Tanuseputro treats most of his dying patients in their own homes. He offers patients his cell phone number and the assurance that he will be there when they need him. These house calls – part palliative care (PC), part hand-holding – are embraced by grateful patients and their families. And they make the Orléans family medicine practice that Tanuseputro shares with his wife stand out. “We are in the minority,” he says of their home visits. What the husband and wife physicians do is relatively rare in Ontario, where most people say they want to die in their own homes but few do. Nearly 70% of Ontario residents die in hospitals or long-term care facilities – some of them in busy emergency rooms waiting for a bed. Lack of access to in-home end-of-life care (EoLC) is key to the discrepancy between wishes and reality when it comes to end of life. Tanuseputro, who is a researcher with the Bruyère Research Institute, is lead author of a new study that draws a direct link between the kind of house calls he routinely makes and the number of Ontario patients dying in hospital beds rather than in their homes.¹ The study ... is the largest of its kind to look at the impact of doctor home visits on where people die. Using records of 264,755 Ontario patients who died between 1 April 2010 and 31 March 2013, Tanuseputro and a team of researchers found that EoLC, including house calls and in-home PC, could reduce a patient's chance of dying in hospital by about. Despite that, the research hers found that fewer than 20% of Ontario residents received a house call from their doctor or in-home PC in the last year of their lives. <https://goo.gl/htr8zV>



INSTITUT DE RECHERCHE
BRUYÈRE
RESEARCH INSTITUTE

1. 'Associations between physician home visits for the dying and place of death...', *Plos One*, published online 15 February 2018. **Full text:** <https://goo.gl/8MPHX5>

N.B. Additional articles on home palliative care in Ontario noted in the 5 February 2018 and 11 December 2017 issues of Media Watch (#549, p.2 and #542, p.1, respectively).

IPCRC.NET International Palliative
Care Resource Center

Back Issues of Media Watch
<http://goo.gl/frPgZ5>

Ontario breaks jurisdictional barriers with vow for First Nations health care

ONTARIO | *The Globe & Mail* (Toronto) – 13 February 2018 – The Ontario government is preparing to announce it is keeping a two-year-old promise to inject hundreds of millions of dollars into First Nations health care and that cash is now flowing to culturally appropriate initiatives including palliative care (PC), primary care and mental wellness. First Nations leaders say more money is still needed to bring the standard of care provided to their people to the level enjoyed by other Canadians. But they give credit to Ontario for breaking down jurisdictional barriers, both with the federal government and with Indigenous communities, to improve a system that has been rife with failure. In May of 2016, the Ontario government said it would spend \$222 million over the next three years to enhance

health care in First Nations communities. The plan was to provide culturally appropriate care delivered largely by Indigenous people themselves. In December, Ontario provided \$55,300 to each of the province's 133 First Nations to improve access to culturally appropriate home and community care. <https://goo.gl/Q4RDWp>

Extract from *The Globe & Mail* article

The province has paid to create or expand 16 Indigenous primary care teams across the province. It has trained hundreds of PC specialists who will work in First Nations communities.

N.B. 'Aboriginal Peoples: Fact Sheet for Ontario,' Statistics Canada, March 2016. <https://goo.gl/ZLvYcB>

Noted in Media Watch 5 February 2018 (#549, p.10):

- *HEALTH ECONOMICS, POLICY & LAW* | Online – 1 February 2018 – '**Medicare and the care of First Nations, Métis and Inuit.**' The Canada Health Act provides for the federal transfer of funding to the provinces/territories, in exchange for their adherence to Medicare's principles of universality, comprehensiveness, portability, accessibility and public administration. Medicare is a decentralized system, managed independently by Canada's provincial and territorial governments, allowing for regional adaptations to fit varying degrees of urbanity, remoteness and needs. The Act is silent on its relationship to the Indigenous health care system. **Abstract (w. list of references):** <https://goo.gl/Wqexyx>

Noted in Media Watch 1 January 2018 (#544, p.1):

- ONTARIO | TV Ontario (Toronto) – 20 December 2017 – '**How redefining palliative care is bringing end-of-life services to First Nations.**' A six-year research project based in Thunder Bay studying four communities has shown that ailing people can stay on reserve and out of hospital for longer with minimal investments in homecare and medical services in the community. While the project's sample size was small, the model's perceived success and potential flexibility is prompting the province to make investments in on-reserve palliative care in the near future. EoLC, which can involve large immediate and tight-knit extended families. <https://goo.gl/qyfq8P>

N.B. Selected articles on palliative care and end-of-life care for the Indigenous peoples of Canada noted in the 4 December and 6 February 2017 issues of Media Watch (#541, pp.1-2 and #498, pp.1-2, respectively).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | 1130 Radio News (Vancouver) – 11 February 2018 – '**Palliative care president airs concerns about Fraser Health Medical Assistance in Dying (MAiD) policy.**' The stalemate continues between the Delta Hospice Society and Fraser Health, over whether hospices in the region should be required to provide assisted dying. Fraser Health has recently delivered a directive to hospices within its jurisdiction, saying they must eventually provide medically assisted death. It's a policy that the Delta Hospice Society is hoping it will be exempt from, but last week a meeting with Fraser

Cont.

Health failed to produce an agreement. Meantime, organizations such as the Canadian Society of Palliative Care Physicians are coming to the hospice society's defence. President David Henderson has fired off a letter to Fraser Health outlining his concerns. He says requiring hospices to provide MAiD would sabotage decades of work to emphasize that palliative care involves helping patients manage symptoms. According to a report by the Canadian Hospice Palliative Care Association, only 16 to 30% of Canadians who die currently have access to or receive hospice palliative and end-of-life care services – depending on where they live.¹ <https://goo.gl/4ZW5kc>

1. 'Fact Sheet: Hospice Palliative Care in Canada,' Canadian Hospice Palliative Care Association, March 2014. Download/view at: <https://goo.gl/tYsc6a>

N.B. Articles on Bill C-277, 'An Act providing for the development of a framework on palliative care (PC) in Canada,' noted in the 18 December 2017 issue of Media Watch (#543, pp.1-2). Additional articles on hospice and PC in Canada, with reference to key studies on end-of-life care (1995-2014), noted in the 18 January 2016 issue of Media Watch (#445, pp.1-2).

[U.S.A.](#)

Doctors learn how to talk to patients about dying

MASSACHUSETTS | *Kaiser Health News* – 12 February 2018 – Hundreds of clinicians at Massachusetts General Hospital in Boston are getting trained to talk to seriously ill patients about their goals, values – and prognoses – while there's time to spare. At the hospital, Dr. Juliet Jacobsen, a palliative care physician, serves as medical director for the Continuum Project, a large-scale effort to quickly train clinicians to have these conversations, document them and share what they learn with one another. The project ramped up in January with the first session in a series that aims to reach 250 primary care providers at the hospital. For patients with advanced cancer, end-of-life (EoL) conversations with clinicians take place a median of 33 days before a patient's death, research shows.¹ When patients have end-stage diagnoses, fewer than a third of families recall having EoL conversations with physicians, another study found.³ That's despite evidence that patients have better quality of life, fewer hospitalizations, more and earlier hospice care and higher satisfaction when they talk to doctors or other clinicians about their values and goals, according to recent research.³ <https://goo.gl/wd6ge4>

1. 'End-of-life care discussions among patients with advanced cancer,' *Annals of Internal Medicine*, 2012;156(3):204-210. [Noted in the 13 February 2012 issue of Media Watch (#240, p.10)] **Full text:** <https://goo.gl/WkJR9x>
2. 'Discussing prognosis with patients and their families near the end of life: impact on satisfaction with end-of-life care,' *Open Medicine*, 2009;3(2):62-70. [Noted in the 22 June 2009 issue of Media Watch (#102, p.8)] **Full text:** <https://goo.gl/DKkHQP>

[Specialist Publications](#)

'Hospice care needs study' (p.6), in *American Journal of Medical Quality*.

'Barriers to accessing palliative care for pediatric patients with cancer: A review of the literature' (p.10), in *Cancer*.

'Surrogates' experiences of engaging in Physician Orders for Life-Sustaining Treatment discussions for persons with advanced dementia' (p.16), in *Journal of the American Association of Nurse Practitioners*.

'Quality of hospice care at home versus in an assisted living facility or nursing home' (p.7), in *Journal of the American Geriatric Society*.

'Characteristics and outcomes of advanced cancer patients who received palliative care at a public hospital compared with those at a comprehensive cancer center' (p.7), in *Journal of Palliative Medicine*.

'Costs at the end of life: Perspectives for North Carolina' (p.7), in *North Carolina Medical Journal*.

Cont.

3. 'Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment,' *Journal of the American Medical Association*, 2008;300(14):1665-1673. [Noted in the 13 October 2008 issue of Media Watch (#66, p.5)] **Full text:** <https://goo.gl/YuwELh>

How drug company money turned patient groups into “cheerleaders for opioids”

USA TODAY | Online – 12 February 2018 – The five biggest opioid manufacturers shelled out more than \$10 million to patient advocacy groups, professional medical societies and affiliated individuals – who then “echoed and amplified” messages that encouraged use of those highly addictive drugs and set the stage for the current opioid epidemic. That’s according to a new Senate committee investigation ... which examined the financial ties between the pharmaceutical industry and outside groups over the last five years, from 2012 through 2017. Among the recipients of drug company largesse: U.S. Pain Foundation, the National Pain Foundation, and the Academy of Integrative Pain Management. The report charges that many of the advocacy groups, buoyed by drug company money, started undercutting state and federal efforts to curb opioid prescribing and using other “opioids-friendly messaging.” The report notes, for example, that the American Academy of Pain Medicine and the American Pain Society have promoted opioids as safe and effective for treating chronic pain and minimized the risk of addiction. Some of the groups and their funders say there's a public health crisis being created by the response to the opioid epidemic. Chronic pain patients say they now have difficulty getting narcotics, which is often the only thing that can address their unremitting pain. <https://goo.gl/jw7boC>

Related

- CALIFORNIA | CBS News (Los Angeles) – 12 February 2018 – ‘**Purdue Pharma says it will stop promoting opioid OxyContin to doctors.**’ More than a decade after Purdue Pharma was first criticized by the federal government for its “aggressive” marketing of the addictive painkiller OxyContin, the company says it will stop promoting the opioid to doctors. <https://goo.gl/xFxJV9>

Noted in Media Watch 4 December 2017 (#541, p.12):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(6):508-513. ‘**Justice in America: Ethical issues in cancer pain control.**’ Pain is common in those with a life-threatening illness, yet barriers to adequate treatment persist. New challenges add to the well-known barriers of limited education, lack of time, and impaired access to expert treatment. The opioid abuse epidemic and the rising rate of deaths related to misuse of opioids present new obstacles to cancer pain relief. Although many of the efforts to reduce the impact of the opioid epidemic are important to the community, there are unintended consequences. **Abstract:** <https://goo.gl/tjPzys>

Noted in Media Watch 13 November 2017 (#538, p.9):

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 6 November 2017 – ‘**Appeal to physicians – opioids have their place. Let’s avoid an unintended tragedy.**’ A well-known tragedy has occurred with respect to opioids – the crisis of overdose deaths from opioids that were obtained from various legitimate and illegitimate sources. This has necessitated urgent government and public action. A second, preventable tragedy is beginning to occur as an unintended consequence of the first. The stigma around opioid use has become so strong that patients, families, and health care practitioners are afraid to receive or prescribe them... **Full text:** <https://goo.gl/VzahC4>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE ATLANTIC* | Online – 12 February 2018 – ‘**At veterans’ homes, aid-in-dying isn’t an option.**’ Proponents of medical aid-in-dying and residents of the Veterans Home of California at Yountville ... are protesting a regulation passed in 2016 by the California Department of Veterans Affairs ... that requires that anyone living in the facilities must be discharged if they intend to use the law. That’s a position shared by most – but not all – states where aid-in-dying is allowed. As more U.S. jurisdictions consider whether to legalize the practice, the status of terminally ill veterans living in state-run homes will loom large. California is not alone. Three other states where aid-in-dying is legal – Oregon, Colorado, and Vermont – prohibit use of lethal medications in state-run veterans’ homes. <https://goo.gl/GBbr1J>

International

Hospice care in Scotland 2017

U.K. (Scotland) | Hospice UK – 14 February 2018 – In 2016-2017 hospices in Scotland directly supported 19,000 people, from new born babies to centenarians. A further 2,400 people accessed bereavement services provided by hospices, and many more were supported as carers and families. This does not mean that everyone who could benefit from expert end of life (EoL) care receives it. In his 2015 report to the Health & Sport Committee, Professor David Clark noted that, using a *per capita* model from England to establish an estimate of those who might benefit from but are currently not receiving palliative care, there are potentially 10,600 people per year in Scotland who are missing out on the right care at EoL.¹ To address this we need a system-wide response; improved awareness of the services available through hospices and who they could benefit, increasing referral rates for some diagnoses, specific programmes to identify and reach underrepresented groups, and greater collaboration across health and social care where people with palliative and EoL needs come into contact with services.

Download/view at: <https://goo.gl/oZuff2>

1. 'We need to talk about palliative care,' Health & Sport Committee, Scottish Parliament, November 2015. [Noted in the 30 November 2015 issue of Media Watch (#438, p.4)] **Download/view at:** <https://goo.gl/ELYrN7>

Noted Media Watch 26 September 2016 (#481, p.4):

- U.K. (Scotland | BBC News – 22 September 2016 – '**A new publication is offering a comprehensive guide to end-of-life care facilities across Scotland.**' The 'Scottish Atlas of Palliative Care' has been compiled by academics based at the University of Glasgow.¹ It includes maps, tables, lists and diagrams showing which services are available, at what level, and where and contains previously-unavailable data on palliative care services across Scotland. <https://goo.gl/zgl68s>

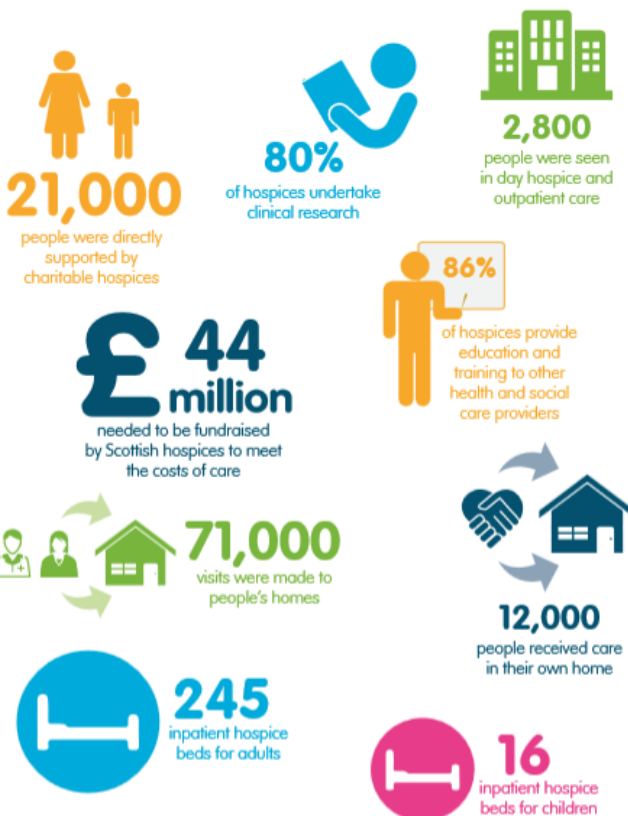
1. 'Scottish Atlas of Palliative Care,' End-of-Life Studies Group, University of Glasgow, September 2016. **Download/view at:** <https://goo.gl/Sf3DCy>

Noted in Media Watch 21 December 2015 (#441, p.8):

- U.K. (Scotland) | STV News (Glasgow) – 18 December 2015 – '**Everyone to have palliative care access, pledges Scottish Government.**' Palliative care will be made available to every Scot, regardless of diagnosis, in a new government strategy¹ backed by a £3.5 million investment addressing what is described as "one of the most challenging issues of the day." It reveals the Scottish Government's plans to provide care for all over the next five years, regardless of age, diagnosis, socio-economic background or postcode. <https://goo.gl/5FMzQP>

1. 'Strategic Framework for Action on Palliative & End-of-Life Care: 2016-2021,' Scottish Government, December 2015. **Download/view at:** <http://goo.gl/CKePjU>

Key statistics



Assisted (or facilitated) death

Representative sample of recent news media coverage:

- FRANCE | *Euro News* (Lyon) – 14 February 2018 – ‘**Where in Europe is assisted suicide legal?**’ Only three countries approve assisted dying as a whole: Belgium, The Netherlands, and Luxembourg. The first two even recognize requests from minors under strict circumstances, while Luxembourg exclude them from the legislation. Countries such as Spain, Sweden, England, Hungary and Norway allow passive euthanasia under strict circumstances. Passive euthanasia is when a patient suffers from an incurable disease and decided not to apply life-longing treatments, such as artificial nutrition or hydration. <https://goo.gl/qhraEU>
- SWITZERLAND | *Swissinfo.com* (Bern) – 14 February 2018 – ‘**Growing number of people sign up for assisted suicide.**’ Every year, thousands of people become members of Exit, the largest assisted suicide organisation in Switzerland. Last year was no exception, with 10,078 new members signing up. If they fulfil certain criteria, members can use the organisation’s services when they decide the time is right to end their life. Exit has 110,391 members in German-speaking Switzerland and in Ticino, according to December 2017 figures. 734 people ended their lives using Exit’s services in 2017, compared to 723 the year before. <https://goo.gl/onfnY1>

Specialist Publications

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

Hospice care needs study

AMERICAN JOURNAL OF MEDICAL QUALITY | Online – 7 February 2018 – As the population ages, the need for hospice care to address the physical, psychological, social and spiritual needs of patients and their families clearly increases. Medical schools have attempted to integrate hospice and palliative medicine (HPM) curricula for more than 20 years and in 2016 the accreditation Council for Graduate Medical Education updated the common program requirements for the subspecialty HPM to support patients’ quality of life and management of factors contributing to the suffering of both terminal patients and their families. Despite these initiatives, gaps in both education and numbers of qualified providers still exist, and hospice remains largely misunderstood by patients and medical professionals alike. A task force convened by the American Academy of Hospice & Palliative Medicine found an acute shortage of HPM physicians and reported that current fellowship programs are insufficient to fill the shortage.¹ Others claim that progress during the past 20 years is at risk without support for academic educators to develop new curriculum and evaluation strategies in palliative medicine. **First page view (w. list of references) at:** <https://goo.gl/nHh6AF>

1. ‘Estimate of current hospice and palliative medicine physician workforce shortage,’ *Journal of Pain & Symptom Management*, 2012;40(6):899-911 [Noted in the 13 December 2010 issue of *Media Watch* (#179, p.9)] **Abstract:** <https://goo.gl/PGQEsn>

Noted in *Media Watch* 5 February 2018 (#549, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 February 2018 – ‘**The growing demand for hospice and palliative medicine physicians: Will the supply keep up?**’ The current U.S. supply of hospice and palliative medicine (HPM) specialists is 13.35 per 100,000 adults 65 and over. Using alternate assumptions for future supply and demand, the authors project need in 2040 will range from 10,640 to almost 24,000 HPM specialist physicians. **Abstract:** <https://goo.gl/jPGwPB>

Cont. next page

Related

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 10 February 2018 – ‘**Quality of hospice care at home versus in an assisted living facility or nursing home.**’ After-death quality-of-care survey results for 7,510 individuals were analyzed to assess relationship between location of care and overall service quality. Most (84.3%) respondents reported that hospice referral had occurred at the right time, and 63.4% rated service quality as excellent. **Abstract:** <https://goo.gl/aiY8Nw>

Noted in Media Watch 20 March 2017 (#504, p.10):

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 14 March 2017 – ‘**Variation in hospice services by location of care: Nursing home versus assisted living facility versus home.**’ Minimal differences were found in overall intensity of service contacts across settings; however, the mix of services were different for patients living at home versus nursing home versus assisted living facility. **Abstract:** <https://goo.gl/PWewbN>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 February – ‘**Characteristics and outcomes of advanced cancer patients who received palliative care at a public hospital compared with those at a comprehensive cancer center.**’ There are limited literature regarding characteristics and outcomes of patients evaluated by palliative care services at public hospitals (PHs). Advanced cancer patients at both institutions [included in this study] frequently had multiple distressing physical and emotional symptoms, although the frequency was higher at the comprehensive cancer center. **Abstract:** <https://goo.gl/DZUY4A>
- *NORTH CAROLINA MEDICAL JOURNAL*, 2018;79(1):43-45. ‘**Costs at the end of life: Perspectives for North Carolina.**’ Many elders require supportive services, with many costs covered by Medicaid. Once terminal illness sets in, palliative care and hospice may help control cost while ensuring quality. This commentary reviews trends in cost at the end of life and describes selected strategies to improve patient-centered care in North Carolina. **Full text:** <https://goo.gl/D7KZU1>

Twenty years of home-based palliative care in Malappuram, Kerala, India: A descriptive study of patients and their caregivers

BMC PALLIATIVE CARE | Online – 14 February 2018 – The well-lauded community-based palliative care (PC) programme of Kerala, India, provides medical and social support, through home-based care, for patients with terminal illness and diseases requiring long-term support. There is, however, limited information on patient characteristics, caregivers and programme performance. A study was conducted in the oldest community-based palliative clinic in Kerala. While 91% of the patients registered in the clinic in 1996 had cancer, its relative proportion came down to 32% in 2016 with the inclusion of dementia-related illness (19%) cardiovascular accidents (17%) and severe mental illness (5%). The changing dynamics over a 20-year period of this PC programme ... highlights the need for similar programmes to remain flexible and adapt their services in response to a growing global burden of non-communicable diseases. While a high death rate is expected in this population, the high proportion of patients choosing to stay in the programme suggests that home-based care is valued within this particular group. A diverse range of clinical and psycho-social support skills are required to assist families and their caregivers when caring for a cohort such as this one. **Full text:** <https://goo.gl/N2FmFg>

Noted in Media Watch 16 January 2017 (#495, p.8):

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2017;23(1):65-70. ‘**Home-based palliative services under two local self-government institutions of Kerala, India: An assessment of compliance with policy and guidelines to local self-government institutions.**’ Despite having made much progress, the program in two local self-government institutions is still short of a public health approach, and major guidelines of the palliative policy seem to have been given a miss. It also lacks the flavor of a community-owned program with a committed organizational structure, dedicated staff and delivery mechanism, seamless care through continuous monitoring, high frequency of visits, and adequate referrals. **Full text:** <https://goo.gl/kuxH98>

Integrating palliative care into neurology services: What do the professionals say?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – Accessed 17 February 2018 – Patient perceptions of palliative care (PC) was identified as a potential barrier to the successful integration of neurology and PC services. It is equally important for neurology professionals to have the right understanding of PC and to recognise the potential benefit of PC for their patients. Indeed, previous studies have demonstrated that the topic of PC can still often lead to anxiety in patients, caregivers as well as healthcare professionals. There is an emphasis on the need for integrated working along with improved education and awareness in order to make PC more recognised and more accessible for non-cancer conditions... As reported by both specialties, resources must be carefully considered and systems developed for calling on PC specialists when truly necessary. The small number of [survey] respondents highlights the challenges of conducting research among busy health professionals... **Full text:** <https://goo.gl/K3V3dh>

Noted in Media Watch 9 October 2017 (#533, p.14):

- *MAYO CLINIC PROCEEDINGS*, 2017;92(10):1592-1601. ‘**Palliative care in neurology.**’ Patients with a variety of neurologic conditions such as Parkinson disease, dementia, amyotrophic lateral sclerosis, brain tumors, stroke, and acute neurologic illnesses have substantial unmet needs that can be addressed through a combination of primary and specialty palliative care (PC). With the rapid growth in PC across the U.S., there are opportunities to improve the PC knowledge of neurology trainees, the delivery of PC to patients with neurologic disease by both neurologists and non-neurologists, and the research agenda for neuro-PC. **Full text:** <https://goo.gl/Zk4adw>

End-of-life chemotherapy: A prisoner’s dilemma?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – Accessed 17 February 2018 – Great advances in the prevention, detection and treatment of cancer continue to improve survival. However, despite much attention focused on end-of-life (EoL) chemotherapy, many patients continue to receive chemotherapy late into their illness, providing minimal benefit and potentially causing harm. The authors describe the prisoner’s dilemma, in the context of palliative oncology, as a framework to partially explain this finding. They believe that this novel perspective will provide valuable and interesting insights to practising clinicians. Almost 10% of patients receive chemotherapy within 2 weeks of dying of cancer, and 60% receive treatment within two months of death. The majority of these patients mistakenly believe that this type of chemotherapy is curative rather than palliative. In fact, EoL chemotherapy has limited benefits and is associated with worse quality of life, more emergency and intensive care interventions and greater financial cost to patients and families. Consequently, the American Society for Clinical Oncology identified reducing EoL chemotherapy as one of the “top five” practices for improving care and cutting costs. Despite these recommendations, large number of patients continue to receive aggressive treatment within their last few days of life. Why do patients continue to receive EoL chemotherapy? **Introductory paragraphs:** <https://goo.gl/HUUD2A>

Noted in Media Watch 18 September 2017 (#530, p.12):

- *EXPERT REVIEW OF QUALITY OF LIFE IN CANCER CARE* | Online – 11 September 2017 – ‘**Gaps in patients’ understanding of palliative chemotherapy. Can we better communicate that treatment is not curative?**’ Misunderstanding in cancer patients receiving chemotherapy is common; 50% of cancer chemotherapy is given with palliative intent. Many patients receiving chemotherapy for incurable cancer may not understand that chemotherapy is unlikely to be curative. Cancer patients expect to share treatment decisions with their oncologist. Provision of a question prompt list and endorsement by physicians enhances patient participation in consultations and promotes patient questions about prognosis. **Abstract:** <https://goo.gl/9bsjhl>



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning p.17.

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

Persistent inequalities in hospice at home provision


BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 14 February 2018 – Many people who wish to support loved ones to die at home may be doing so with little or no prior experience of death and dying to draw on. With ageing populations and rising multi-morbidity later in life, the need for palliative care (PC) is increasing. As the trend towards fewer people dying in hospital continues in many, though not all countries, services such as Hospice at Home (H@H), which exist to support carers and patients emotionally and physically to enable a natural acceptance and dignified end of life (EoL), are becoming an increasingly vital resource to allow people to die at home. This study has identified the important roles that a H@H service plays in the care of people approaching the EoL and in a detail that has not been reported before. It has also highlighted a dismaying gap between demand for such a service and the available supply. **Full text:** <https://goo.gl/5XvdgS>

Noted in Media Watch 16 November 2015 (#436, p.18):

- *PLOS ONE* | Online – 10 November 2015 – ‘**Do patients want to die at home? A systematic review of the U.K. literature, focused on missing preferences for place of death.**’ It is unknown what proportion of U.K. patients prefer to die at home. The authors found no clear difference between preferences for home and the diagnosis of patients. Ultimately, preferences for place of death appear to depend on who is asked the question; what, where, why and when they are asked, and how those without an answer are included. **Full text:** <https://goo.gl/vPZUZR>

Related

- *FUTURE HEALTHCARE JOURNAL*, 2018; 5(1):7-9. ‘**Dying at home the Midhurst way.**’ A model of a consultant-led palliative care (PC) community team was set up following the closure of a specialist PC inpatient unit in Midhurst, with the aim of providing that same level of care to patients in their own homes, care homes and community hospitals. The Macmillan Midhurst Service costs an average of less than £3,000 per patient and enables 85% of referred patients to die in their preferred place. Evaluations of the service have highlighted benefits to patients and families as well as cost reductions to the National Health Service of around 20% when patients are referred early. **Full text:** <https://goo.gl/FrCKqn>

Future Healthcare Journal

Several articles in the February 2018 issue of *Future Healthcare Journal*, a publication of the Royal College of Physicians, focus on different aspects of end-of-life care. **Contents page:** <https://goo.gl/EbNX8y>

N.B. The latest issue of the College's *Commentary* also focuses on end-of-life care. **Read the magazine online at:** <https://goo.gl/5Vg6gZ>

End-of-life care in The Netherlands

Interventions in hospitalised patients with cancer: The importance of impending death awareness

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 9 February 2018 – Burdensome and futile interventions with the aim of prolonging life should be avoided in dying patients. However, current clinical practice has hardly been investigated. The authors examined the number and type of diagnostic and therapeutic medical interventions in hospitalised patients with cancer in their last days of life. In addition, they investigated if physician awareness of impending death affected the use of these interventions. Many patients with cancer who died in hospital [i.e., the patient population studied] receive diagnostic and therapeutic interventions in the last days of life of which their advantages are questionable. To improve end-of-life care, medical care should be adapted. **Abstract:** <https://goo.gl/TSozvC>

Cont.

Noted in Media Watch 17 July 2017 (#521, p.4):

- U.S. | *The New York Times* – 11 July 2017 – ‘**The gentler symptoms of dying.**’ While some of the symptoms of dying, like the death rattle, air hunger and terminal agitation, can cause alarm in witnesses, other symptoms are more gentle. The human body’s most compassionate gift is the interdependence of its parts. As organs in the torso fail, the brain likewise shuts down. With the exception of the minority of people who suffer sudden death, the vast majority of us experience a slumberous slip-page from life. <https://goo.gl/Szo5Vf>

Noted in Media Watch 26 June 2017 (#518, p.3):

- U.S. | *The New York Times* – 20 June 2017 – ‘**The symptoms of dying.**’ Dying has its own biology and symptoms. It’s a diagnosis in itself. While the weeks and days leading up to death can vary from person to person, the hours before death are similar across the vast majority of human afflictions. Some symptoms, like the death rattle, air hunger and terminal agitation, appear agonizing, but aren’t usually uncomfortable for the dying person. They are well-treated with medications. With hospice availability increasing worldwide, it is rare to die in pain. <https://goo.gl/3gGgth>

American Cancer Society

Barriers to accessing palliative care for pediatric patients with cancer: A review of the literature

CANCER | Online – 16 February 2018 – Although many of the 16,000 children in the U.S. diagnosed who are with cancer each year could benefit from pediatric palliative care (PC), these services remain under-used. Evidence regarding the barriers impeding access to comprehensive PC is dispersed in the literature, and evidence specific to pediatric oncology remains particularly sparse. This review synthesized the existing literature regarding these barriers and the strategies offered to address them. Barriers to accessing pediatric PC were categorized according to the four levels of a modified socio-ecological model (i.e., barriers related to policy/payment, health systems, organizations, and individuals). Major themes identified at each level included: 1) The lack of consistent and adequate funding mechanisms at the policy/payment level; 2) The lack of pediatric PC programs and workforce at the health systems level; 3) Difficulties integrating PC into existing pediatric oncology care models at the organizational level, and, 4) The lack of knowledge about pediatric PC, discomfort with talking about death, and cultural differences between providers and patients and their families at the individual level. Recommendations to address each of the barriers identified in the literature are included. **Abstract:** <https://goo.gl/b3WAI5>

Noted in Media Watch 12 February 2018 (#550, p.10):

- *PEDIATRIC & BLOOD CANCER* | Online – 8 February 2018 – ‘**Perceptions of barriers and facilitators to early integration of pediatric palliative care: A national survey of pediatric oncology providers.**’ Most respondents agreed the palliative care team does not negatively impact the role of the oncologist; however, there were concerns optimal patient care may be limited by pediatric oncologists’ need to control all aspects of patient care. Oncologists, more than any provider group, identified that the emotional relationship they form with the patients and families they care for influences what treatment options are offered and how these options are conveyed. **Abstract:** <https://goo.gl/goZZUL>

Noted in Media Watch 1 January 2018 (#544, p.11):

- *DEATH STUDIES* | Inprint – Accessed 20 December 2017 – ‘**Palliative care professionals’ perceptions of barriers and challenges to accessing children’s hospice and palliative care services in South East London: A preliminary study.**’ According to the palliative care (PC) professionals interviewed several factors contribute to families’ decisions to not seek PC for their children. These included misconceptions and biases of such care. What also emerged is that families wishing to use PC services, particularly for onsite hospice services, encounter numerous challenges and barriers. These include problems with transportation, limited capacity of PC services which may lead to unreliability of respice care. **Abstract:** <https://goo.gl/waeYgo>

An overview of the spiritual importances of end-of-life care among the five major faiths of the U.K.

CLINICAL MEDICINE, 2018;18(1):23-31. For many who pertain to particular theological paradigms, their faith cannot be compartmentalised, but is mobilised to inform all aspects of their being, most notably their ethical and moral persuasions. As clinicians, the concept that there are good and bad deaths is already known; understanding the origin and depth of non-physical suffering, and aiming to alleviate it is not possible without learning the individual experiences and beliefs that go with it. Spiritual care forms a fundamental consideration in the endeavor to address the holistic experience of those patients receiving palliative care (PC). Good PC seeks to promote the wellbeing and priorities of those with faltering health in a way that continues to support individualised notions of self-determination. The last few decades have resulted in a multicultural and multi-ethnic patient

population. Addressing the spiritual and physical needs of patients allows healthcare professionals to deliver truly holistic care. Exploring and understanding the specific nuances of the five major religions of the U.K. provides healthcare professionals the opportunity to comfort the religiously observant patient at the end of life.¹

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



Journal of
Clinical Medicine

Several articles in the February 2018 issue of *Clinical Medicine*, a publication of the Royal College of Physicians, focus on different aspects of end-of-life care. **Journal contents page:** <https://goo.gl/Satdc9>

1. Christianity, Islam, Hinduism, Sikhism and Judaism.

Noted in Media Watch 23 October 2017 (#535, p.13):

- *SCANDINAVIAN JOURNAL OF PUBLIC HEALTH* | Online – 16 October 2017 – ‘**Religious affiliation at time of death: Global estimates and projections.**’ The authors compiled data on demographic information and religious affiliation from more than 2,500 surveys, registers and censuses covering 198 nations/territories. They present estimates of religious affiliation at the time of death as of 2010, projections up to and including 2060, taking into account trends in mortality, religious conversion, intergenerational transmission of religion, differential fertility, and gross migration flows, by age and sex. **Abstract:** <https://goo.gl/i8zpxq>

Noted in Media Watch 23 January 2017 (#496, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 19 January 2017 – ‘**A systematic review of religious beliefs about major end-of-life issues in the five major world religions.**’ The authors’ search strategy generated 968 references, 40 of which were included for this review. Whenever possible, they organized the results into five categories that would be clinically meaningful for palliative care practices at the end-of-life (EoL): 1) Advanced directives; 2) Euthanasia and physician-assisted suicide; 3) Physical requirements (artificial nutrition, hydration, and pain management); 4) Autopsy practices; and, 5) Other EoL religious considerations. **Abstract:** <https://goo.gl/0Lh72z>

Research involving dying persons: Time to reconsider?

COLLEGIAN (Australian Journal of Nursing Practice, Scholarship & Research), 2018;25(1):1-2. Using research to generate evidence to inform clinical practice is a position adopted almost universally in healthcare, with health care organisations, policymakers and clinicians using research evidence to improve the quality of care. Yet, when it comes to palliative and end-of-life (EoL) care, the situation may be different. Research involving the dying, whether conducted in palliative care settings or elsewhere, is often considered ethically challenging and controversial. This is because of concern about the actual or

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potential vulnerability of persons approaching the EoL and whether the dying person can or should be involved in research. Yet, the caution associated with research participation for those who are dying, might need to be reconsidered. Despite concern from ethical review boards, researchers, clinicians and consumers that research involving dying persons might be intrusive, inappropriate or unethical, the research evidence suggests that dying persons who have participated in research did so with very good reason. **Full text:** <https://goo.gl/kDM3fC>

Related

- *BRITISH SUPPORTIVE & PALLIATIVE CARE* | Online – Accessed 17 February 2018 – ‘**International palliative care research in the context of global development: A systematic mapping review.**’ 184 studies were included, published across 75 different academic journals. Research emanates from and focuses on all world regions and there is increasing focus on the global level. International palliative care (PC) research is a relatively new, but growing field. However, many gaps in the evidence base remain and PC research continues to take place outside broader discourses of international development. **Abstract:** <https://goo.gl/fqgrwF>

Noted in Media Watch 11 December 2017 (#542, pp.9-10):

- *CANCER NURSING*, 2018;41(1):86-87. ‘**Surprised by benefit in pediatric palliative care research.**’ As the benefits and risks for children and families participating in PC research are largely unknown, most clinicians and review boards focus on the potential for harm. Institutional review boards may be reluctant to approve research for vulnerable populations using a biomedical model to assess harm without equally examining the perceived benefit of social and behavioral research findings. We have witnessed this well-intended focus on hypothetical harm become a fear of potential harm, which translates into a resistance to approve pediatric PC research. **Full text:** <https://goo.gl/zyw7r9>

Noted in Media Watch 2 October 2017 (#532, p.12):

- *PALLIATIVE MEDICINE*, 2017;31(9):778-780. ‘**When to provide palliative care: The challenge of (re)searching where the light is dim.**’ In the last decade, there has been a sea change in the direction of research and practice in palliative care (PC). The first wave of trials of specialised PC interventions, beginning in the 1980s, aimed to show the effectiveness of involvement of PC for patients with life-threatening illness at the end of life, when PC was traditionally provided. These studies had methodological challenges that were virtually insurmountable, including difficulties with recruitment, attrition, and cross-over from the control to the intervention group. **Full text:** <https://goo.gl/K6R9Em>

Noted in Media Watch 9 March 2009 (#87, p.9):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2009;12(3):215-217. ‘**The culture of research in palliative care: “You probably think this song is about you.”**’ “But is it right?” If my memory can be trusted, the question came after a presentation by Eduardo Bruera on the importance of research in palliative care. The nurse asking this question did so, not in a way that felt dismissive or punitive, but rather, with a sense of genuine caring and concern. After all, people approaching death have limited time and energy; did we really want to be asking them, indeed, was it right to be asking them to expend effort in answering our research questions? **Abstract:** <https://goo.gl/KKhdFT>

Lay patient navigators’ perspectives of barriers, facilitators and training needs in initiating advance care planning conversations with older patients with cancer

JOURNAL OF PALLIATIVE CARE | Online – 12 February 2018 – Respecting Choices® is an evidence-based model of facilitating advance care planning (ACP) conversations between health-care professionals and patients. However, the effectiveness of whether lay patient navigators can successfully initiate Respecting Choices® ACP conversations is unknown. A cohort of lay patient navigators underwent Respecting Choices® training and were tasked to initiate ACP conversations with Medicare beneficiaries diagnosed with cancer. This evaluation identifies three levels – patient, lay navigator, and organizational

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factors in addition to training needs that influence ACP implementation. Key facilitators included physician buy-in, patient readiness, and navigators' prior experience with end-of-life decision-making. Lay navigators' perceived challenges to initiating ACP conversations included timing of the conversation and social and personal taboos about discussing dying. **Abstract:** <https://goo.gl/GGeCjw>

Noted in Media Watch 1 January 2018 (#539, p.12):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 December 2017 – ‘**Respecting Choices® and related models of advance care planning: A systematic review of published evidence.**’ The authors found that there is a low level of evidence that Respecting Choices® (RC) and derivative models increase the incidence and prevalence of advance directive and Physician Orders for Life-Sustaining Treatment completion. Evidence is mixed, inconclusive, and too poor in quality to determine whether RC and derivative models change the consistency of treatment with wishes and overall health-care utilization in the end of life. **Abstract:** <https://goo.gl/pnq22k>

Related

- *BMC GERIATRICS* | Online – 14 February 2018 – ‘**How to achieve the desired outcomes of advance care planning in nursing homes: A theory of change.**’ The authors created a Theory of Change map that describes how and in what circumstances advance care planning (ACP) should be implemented and organised in nursing homes to achieve its desired long-term outcomes. They explicitly state which intervention components should be part of this ACP intervention. The Theory of Change map provides the first comprehensive rationale of how ACP is expected to work in nursing homes... **Full text:** <https://goo.gl/qdbtNE>
- *JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY*, 2018,7(1):112-119. ‘**Advance care planning discussions with adolescent and young adult cancer patients admitted to a community palliative care service: A retrospective case-note audit.**’ This study indicates end-of-life care preferences for this unique cohort may differ from those of the adult population and need to be captured and understood. An advance care planning document incorporating a discussion regarding goals of care, preferred location of care, preference for place of death, and consent to future intervention, including cardiopulmonary resuscitation and prompts for review, could assist in pursuing this objective. **Abstract:** <https://goo.gl/s2bNfh>

A moment for compassion: Emerging rhetorics in end-of-life care

MEDICAL HUMANITIES | Online – 10 February 2018 – “Compassion” has become the flagship concept to be fostered in the delivery of end-of-life care (EoLC), and a rallying call for social action and public health intervention. The authors examine the emerging rhetorics of compassion as they relate to EoLC and offer a critique of the expanding discourse around it. They argue, even where individuals “possess” compassion or are “trained” in it, there are difficulties for compassion to flow freely, particularly within Western society. This relates to specific socio-political structural factors that include the sense of privacy and individualism in modern industrialised countries, highly professionalised closed health systems, anxiety about litigation on health and safety grounds, and a context of suspicion and mistrust within the global political scenario. We must then ask ourselves whether compas-

sion can be created intentionally, without paying attention to the structural aspects of society. One consequence of globalisation is countries in the global South are rapidly trying to embrace the features of modernity adopted by the global North. The authors argue unrealistic assumptions have been made about the role of compassion in EoLC and these idealist aspirations must be tempered by a more structural assessment of potential. Compassion that is not tied to realistic action runs the risk of becoming empty rhetoric. **Full text:** <https://goo.gl/VGPT1C>

Worth Repeating

‘**Compassion: A scoping review of the healthcare**’ (p.17), in *BMC Palliative Care*.

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Noted in Media Watch 4 December 2017 (#541, p.6):

- *BMC PALLIATIVE CARE* | Online – 1 December 2017 – ‘**Compassionate collaborative care: An integrative review of quality indicators in end-of-life care.**’ Compassionate collaborative care (CCC) is an emerging, complex concept. Although limited by a lack of strong empirical evidence, it is of growing importance for healthcare quality. This integrative review suggests that CCC is inextricably linked to the inherent values, needs and expectations of patients, families and healthcare providers. Communication, shared decision-making and goal setting comprise the overarching processes, while development and satisfaction are overarching outcomes. **Full text:** <https://goo.gl/smV1xn>

Noted in Media Watch 25 January 2016 (#446, p.8)

- *BMC PALLIATIVE CARE* | Online – 19 January 2016 – ‘**Compassion: A scoping review of the healthcare literature.**’ The importance of compassion within healthcare, while seemingly self-apparent and frequently referenced in the literature, has received little in the way of empirical attention. Important clinical studies are emerging and are collectively contributing to a body of evidence that brings insight to compassion in clinical care. However, these studies often rely on preconceived theoretical definitions of compassion that lack specificity, clinical applicability, conceptual validity, and fail to adequately incorporate the understandings and experiences of patients. **Full text:** <http://goo.gl/CoL1EU>

Integrated palliative care is about professional networking rather than standardisation of care: A qualitative study with healthcare professionals in 19 integrated palliative care initiatives in five European countries

PALLIATIVE MEDICINE | Online – 13 February 2018 – Comparisons of how integrated palliative care (PC) is implemented across four key domains of integrated care – content of care, patient flow, information logistics and availability of (human) resources and material – are lacking. A total of 19 group interviews were conducted (2 in Belgium, 4 in The Netherlands, 4 in the U.K., 4 in Germany and 5 in Hungary) with 142 healthcare professionals from several integrated PC initiatives in the five European countries. The dominant strategy for fostering integrated PC is building core teams of PC specialists and extended professional networks based on personal relationships, shared norms, values and mutual trust, rather than developing standardised information exchange and referral pathways. Providing integrated PC with healthcare professionals in the wider professional community appears difficult, as a shared proactive multidisciplinary PC approach is lacking, and healthcare professionals often do not know PC professionals or services. Achieving better PC integration into regular healthcare and convincing the wider professional community is a difficult task that will take time and effort. Enhancing standardisation of PC into education, referral pathways and guidelines and standardised information exchange may be necessary. External authority (policy makers, insurance companies and professional bodies) may be needed to support integrated PC practices across settings. **Full text:** <https://goo.gl/SK92iW>

Noted in Media Watch 12 February 2018 (#550, p.15):

- *PALLIATIVE MEDICINE* | Online – 5 February 2018 – ‘**Integrated palliative care networks from the perspectives of patients: A cross-sectional explorative study in five European countries.**’ About 33% [of study participants] reported contact with a palliative care (PC) specialist and 48% with a PC nurse. Relationships with PC specialists were rated significantly higher than other physicians. Compared to patients with cancer, patients with chronic obstructive pulmonary disease and chronic heart failure had significantly lower odds of reporting contact with PC specialists and patients with chronic obstructive pulmonary disease had significantly lower odds of reporting contact with PC nurses. **Full text:** <https://goo.gl/5Rj7yP>

Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

“People don’t understand what goes on in here”: A consensual qualitative research analysis of inmate-caregiver perspectives on prison-based end-of-life care

PALLIATIVE MEDICINE | Online – 12 February 2018 – There is growing research support for prison-based end-of-life care (EoLC) programs that incorporate inmate peer caregivers as a way to meet the needs of the elderly and dying who are incarcerated. All study participants were male, over the age of 18, and also incarcerated at Briarcliff Correctional Facility, a maximum security, state-level correctional facility [in New York State]. Five over-arching and distinct domains emerged; this manuscript focuses on the following three: 1) Program description; 2) Motivation; and, 3) Connections with others. Findings suggest that inmate-caregivers believe they provide a unique and necessary adaptation to prison-based EoLC resulting in multi-level benefits. These additional perceived benefits go beyond a marginalized group gaining access to patient-centered EoLC and include potential inmate-caregiver rehabilitation, correctional medical staff feeling supported, and correctional facilities meeting EoLC mandates. Additional research is imperative to work toward greater standardization of and access to EoLC for the incarcerated. **Abstract:** <https://goo.gl/Spu1Qv>

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 February 2018) can be downloaded/viewed at Palliative Care Network-e: <https://goo.gl/YLckx6>

Palliative care for dementia

PSYCHIATRIC CLINICS OF NORTH AMERICA, 2018;14(1):141-151. With the increase of the elderly population and increasing burden of dementia care, one may consider the need for palliative and hospice services as an urgent public health priority, particularly given that Alzheimer’s disease is now the sixth leading cause of death in the U.S. This public health need is underscored by the severe burden of emotional distress endured by family caregivers and the potential for relief afforded by appropriate end-of-life (EoL) services in dementia. EoL services have been historically created for the context of cancer care, with less of a focus on dementia, although this has changed considerably in recent years. For example, in 1995, less than 1% of hospice patents were observed to have a primary diagnosis of dementia, whereas almost 15% of all hospice enrolments in 2014 were in the context of dementia care. Despite this reassuring rapid increase, there remain challenges in ensuring that patients with dementia are given the chance for the best possible care at the EoL. **Introduction:** <https://goo.gl/j5jE5q>

Related

- *BMC PALLIATIVE CARE* | Online – 13 February 2018 – ‘**A painful experience of limited understanding: Healthcare professionals’ experiences with palliative care of people with severe dementia in Norwegian nursing homes.**’ The authors found healthcare professionals’ experiences of providing palliative care to people with severe dementia to be painful. To be able to understand the patients better, long-term familiarity and knowledge of how to “read” and observe patients with severe dementia are necessary. **Full text:** <https://goo.gl/GMjnkY>

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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>

- *JOURNAL OF THE AMERICAN ASSOCIATION OF NURSE PRACTITIONERS*, 2018;30(2):69-77. **'Surrogates' experiences of engaging in Physician Orders for Life-Sustaining Treatment discussions for persons with advanced dementia.** Study participants reported that clear explanations of clinical information and the opportunity to ask questions and reiterate what they heard were helpful in making treatment decisions. Moreover, surrogates reported feeling respected and understood when providers expressed concern for them or their family member with advanced dementia and asked them about their emotional responses to decision making. **Abstract:** <https://goo.gl/mPHXvd>

N.B. Additional articles on palliative and end-of-life care for people living with Alzheimer's and other forms of dementia noted in 29 January 2018 issue of Media Watch (#548, pp.14-15).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BRITISH MEDICAL BULLETIN* | Online – 12 February 2018 – **'Death on demand? An analysis of physician-administered euthanasia in The Netherlands.'** Physician-administered euthanasia (PAE) was legalized, along with physician-assisted suicide (PAS), in The Netherlands in 2001. There is a general openness about the practice of PAE/PAS and an avoidance of misleading euphemisms. Areas of controversy include rising numbers of annually reported deaths from PAE and uncertainty over actual numbers; movement away from the principle that euthanasia must take place within an established doctor-patient relationship; increasing extension of the 2001 law to people with mental health conditions, dementia and multiple co-morbidities; and, nature of the post-event scrutiny applied to reported cases. Growing points include: the predominance of PAE over PAS where both are legalized raises questions over how these two acts are perceived and whether there are implications for such laws. The authors ask: Are the criteria for PAE/PAS in the 2001 law appropriate for a law of this nature? What should be the respective roles of the second-opinion doctors and the review committees? **Abstract:** <https://goo.gl/T9qqYk>
- *CANADIAN PHARMACISTS JOURNAL* | Online – 9 February 2018 – **'Medical assistance in dying: Examining Canadian pharmacy perspectives using a mixed-methods approach.'** The authors conducted an analysis of pharmacy guidelines, position statements and standards of practice from pharmacy regulatory authorities across Canada. In addition, the Ontario Pharmacists Association surveyed its members (including pharmacists, pharmacy technicians and pharmacy students) about their perceptions of medical assistance in dying (MAiD). Most pharmacy regulatory authorities have provided direction and resources to their pharmacists. Ontario pharmacists and pharmacy technicians are willing to dispense MAiD medications; however, additional support in the form of professional development may be necessary based on participants' desire for education coupled with their perceived lack of knowledge. **Full text:** <https://goo.gl/wg4G4S>
- *FUTURE HEALTHCARE JOURNAL*, 2018;5(1):30-34. **'Physicians' views on current legislation around euthanasia and assisted suicide: Results of surveys commissioned by the Royal College of Physicians.'** Despite a number of bills and high-profile court cases in support of assisted dying, it continues to be an offence under U.K. law. In both 2006 and 2014, the majority of Royal College of Physicians (RCP) members and fellows opposed a change in current legislation on assisted dying and favoured improvements in palliative care. Therefore, the RCP opposes any change in current legislation surrounding physician-assisted suicide and maintains that good palliative and end-of-life care is the mainstay in providing patients with a good and dignified death. **Full text:** <https://goo.gl/AQTpZe>
- *FUTURE HEALTHCARE JOURNAL*, 2018;5(1):35-36. **'End-of-life care means exactly what it says: Palliative care is about care at the end of life, not about ending life.'** Why do most doctors oppose being licensed to provide lethal drugs to their patients to assist their suicide? This is not, as some allege, about religion. While many people with religious beliefs oppose legalisation of assisted suicide, so do many with no such beliefs. This debate is about public safety, not about personal morality. Opposition to assisted suicide is highest among those most closely involved in care of the dying. In the same year (2014) in which the Royal College of Physicians reaffirmed its opposition to a change in the law, a survey of its membership by the Association for Palliative Medicine revealed 82% opposition to a change in the law and only 4% of members willing to participate in such practices if ever they were to be legalised. **Full text:** <https://goo.gl/14tn6v>

Worth Repeating

Compassion: A scoping review of the healthcare literature

BMC PALLIATIVE CARE | Online – 19 January 2016 – The importance of compassion within healthcare, while seemingly self-apparent and frequently referenced in the literature, has received little in the way of empirical attention over the past quarter century. Important clinical studies are emerging and are collectively contributing to a body of evidence that brings insight to compassion in clinical care. However, these studies often rely on preconceived theoretical definitions of compassion that lack specificity, clinical applicability, conceptual validity, and fail to adequately incorporate the understandings and experiences of patients. As a result, compassion is arguably one of the most referenced principles of quality care for which there is little empirical evidence. Compassion is inextricably linked to the inherent qualities of clinicians being actualized through acknowledgment, engagement and action in response to patient suffering. Clinicians' capacity for compassion is largely determined by their baseline qualities, qualities that can be either nurtured or eroded within clinical and educational settings. While this review identifies a multiplicity of directions for future research, two directions seem paramount. First, there is a need to reset the empirical foundation of compassion research by establishing its conceptual specificity, thereby providing a scientific base to conduct future research on the topic marked by validity and rigor. Second, there is a pressing need for applied research, investigating compassion within the clinical setting, as it is at the bedside that compassion seems to either flourish or falter. Above all, future research on the nature of compassion and its application in clinical practice needs to incorporate the perspective of patients, who desperately desire and increasingly expect compassion to be a core component of their healthcare experience. **Full text:** <http://goo.gl/CoL1EU>

Media Watch: Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/br6Xci>

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

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

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

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

Asia

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

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

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>

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

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

Europe



EUROPEAN JOURNAL OF PALLIATIVE CARE: <https://goo.gl/sBTcJS>

[November/December 2017 issue (Scroll down to 'Vulnerable populations: From the homeless to the unbefriended')]

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

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

Media Watch: Editorial Practice

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

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

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.

[Search Back Issues of Media Watch @ http://goo.gl/frPgZ5](http://goo.gl/frPgZ5)

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