

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 ‘Ambulatory advanced cancer patients’ and oncologists’ estimates of life expectancy are associated with patient psychological characteristics but not chemotherapy use’ (p.13), in *Journal of Palliative Medicine*.

Canada

Assisted dying was supposed to be an option. To some patients, it looks like the only one

MACLEAN'S | Online – 22 June 2018 – Canadians were asked in 2016 to accept what is now called Medical Assistance in Dying (MAiD) as standard practice in the health-care system. But as the second anniversary of the federal law sanctioning assisted suicide passes this month, ambiguities embedded in the new regulatory regime are turning end-of-life care (EoLC) into a troubling leap of faith for doctors and patients alike. Even the Collège des Médecins in Quebec, which sped ahead with its own statute in advance of Ottawa's Bill C-14, has sounded a strong warning note about patients “choosing” MAiD purely because their preference for palliative care (PC) isn't available. “EoLC cannot be limited simply to medical assistance in dying,” Collège President Dr. Charles Bernard writes in recently published letter to provincial Health Minister Gaétan Barrette. “That option makes no sense, from a medical point of view, unless it is part of a robust and complete system of PC in Quebec.” Yet provincial foot-dragging on plans to substantially expand PC services is actually denying patients the very choice that was promised in the shift to MAiD, and making it increasingly problematic to discern which patients truly wanted to have a doctor deliberately end their life, Bernard says. <https://goo.gl/7TdFZa>

Number of Canadians choosing medically assisted death jumps 30%

CBC NEWS | Online – 21 June 2018 –There were 1,523 medically assisted deaths in Canada in the last six-month reporting period – a nearly 30% increase over the previous six months. Cancer was the most common underlying medical condition in reported assisted death cases, cited in about 65% of all medically assisted deaths, according Health Canada.¹ Using data from Statistics Canada, the report shows medically assisted deaths accounted for 1.07% of all deaths in the country over those six months. That is consistent with reports from other countries that have assisted death regimes, where the figure ranges from 0.3 to four per cent. Since Quebec's assisted death law and the federal legislation came into force two years ago, 3,714 Canadians have received medical aid in dying. <https://goo.gl/DtRGAX>

1. ‘Third Interim Report on Medical Assistance in Dying,’ Health Canada, June 2018. **Download/ view at:** <https://goo.gl/qY3MJy>

Cont.

Related

- ALBERTA | *The Edmonton Journal* – 18 June 2018 – ‘**Covenant Health walks ethical tightrope between Canadian, canon law on assisted death.**’ In policy and in public, Covenant Health maintains a hard line against medical aid in dying (MAiD), two years after a new Canadian law on assisted suicide came into force. Alberta’s Catholic health provider requires patients to leave its hospitals, nursing homes and hospice beds to receive the service, or even be assessed for eligibility. Yet behind the scenes, internal communications obtained by Postmedia show a health organization that has wrestled with dissension, doubt and sensitivity to criticism as it tries to walk an ethical tightrope between federal and canon law, and the needs of patients. Even as its official stance has been characterized as lacking in compassion, evidence shows Covenant has quietly made concessions that have had the effect of facilitating the medical aid in dying process for patients – despite the risk such activities could be viewed as complicity in assisted death. <https://goo.gl/csKo3h>

Noted in Media Watch 22 January 2018 (#547, p.2):

- ALBERTA | Global TV News (Calgary) – 14 January 2018 – ‘**37 Albertans transferred after faith-based facilities refused medically assisted deaths.**’ The Alberta model is being called a success by supporters of assisted death. It’s an integrated service where patients can contact one navigator in their area and be accompanied through the whole process. The policies of faith-based centres have created barriers. Thirty-seven patients in Alberta have had to be transferred from those centres. Among them are hospitals operated by Catholic-based health agency Covenant Health. <https://goo.gl/JecYy9>

N.B. Additional articles, reports, etc., on faith-based hospitals *vis-à-vis* medical assistance in dying noted in the 15 January 2018 issue of Media Watch (#546, pp.1-2)]

Federal correctional investigator: Needs of aging prisoners not being met

THE OTTAWA CITIZEN | Online – 22 June 2018 – Some halfway houses should be converted to hospices and nursing homes to accommodate growing numbers of federal inmates developing dementia and dying in prison, says federal correctional investigator Ivan Zinger. The Office of the Correctional Investigator, along with the Canadian Human Rights Commission, are jointly investigating what they say is “systemic discrimination” against aging, elderly offenders (50 and older). After years of calling for a policy on older offenders, Zinger said the joint investigation was launched partly in response to the case of an inmate with dementia who, after being in a halfway house for nine years without incident, was sent back to prison, where he died. The inmate, whose dementia had worsened, took his uninsured car for a ride. Police found him not knowing where he was or who he was. His parole was suspended and he went back to prison, where he remained until his death. Officials said they were unable to find a place to look after him – the halfway house wasn’t equipped and local care homes refused to take him. Zinger said older offenders who are dying or have serious, complex medical issues and no longer pose a threat should be placed in the community. Providing palliative care in the community would be a lot cheaper than the \$115,000 annual cost of maintaining a federal prisoner, he noted. <https://goo.gl/XVJHWJ>

Noted in Media Watch 26 February 2018 #552, p.2):

- THE CANADIAN PRESS | Online – 19 December 2017 – ‘**Aging inmates: Correctional Service of Canada has strategy in the works.**’ Canada’s prison population is getting greyer, and the Correctional Service of Canada expects to soon complete a strategy for how to deal with aging inmates. The Office of the Correctional Investigator – the ombudsman for federal prisoners – has been pressing the service to do that for several years. <https://goo.gl/x4RAuF>

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 May 2018) can be downloaded/viewed at: <https://goo.gl/YLckx6>



Media Watch Online

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

U.S.A.

When a health insurer also wants to be a hospice company

THE NEW YORK TIMES | Online – 22 June 2018 – Death has always been lucrative enterprise, whether it involves mahogany caskets or teams of estate and tax lawyers. But hospice, the business of caring for those who are nearing death, has become a booming multibillion-dollar industry that is attracting more and more for-profit companies, including one of the nation's major insurers. That insurer, Humana, is making an unusual bet beyond the current strategy of health insurers to merge with pharmacies or buy up doctors' practices. In teaming up with two investment firms, Humana plans to buy two hospice chains that together would create the industry's biggest operator with hundreds of locations in dozens of states. But a spate of government lawsuits charging negligence and malfeasance against some hospice providers underscores the risks of profiting from the dying: Companies have been accused of signing up people who are not terminally ill, denying visits from a nurse or even refusing a needed trip to the hospital. While people getting hospice care may be at less risk for getting medical tests and treatments they do not need or want, they could get too little care, said Dr. Joan Teno, a professor of medicine and a health services researcher at the Oregon Health & Science University. <https://goo.gl/1iboK3>

Noted in Media Watch 11 June 2018 (#567, p.8):

- *HOME HEALTH CARE NEWS* | Online – 4 June 2018 – '**2017 hospice and home health Medicare utilization trends.**' Compared to home health care, hospice had significant growth in 2017, with 1.3 million Medicare enrollees – a 6.5% jump from 2016. As the Medicare population grows older, hospice admissions will significantly increase even if no other change drivers (such as physician referral patterns or increasing numbers of hospices) are present. Part of the growth in hospice utilization is attributable to the rise in the number of for-profit hospices, according to the Centers for Medicare & Medicaid Services. For-profit hospices made up 30% of the 2,255 hospices in 2000; by 2016, that proportion jumped to two-thirds of the nearly 4,400 hospices in operation. **Full text:** <https://goo.gl/9Kq4T4>

N.B. Additional articles on the hospice "market" in the U.S. noted in the 15 January 2018 and 6 November 2017 issues of Media Watch (#546, p.3 and #537, p.3, respectively).

The positive death movement comes to life

THE NEW YORK TIMES | Online – 22 June 2018 – Death cafes, death doulas, 'Ask a Mortician,' Death-Lab – once the province of goth subculture, death is having a moment in the sun. <https://goo.gl/UwFoQ3>

Specialist Publications

'Connecting personal experiences of loss and professional practices in advance care planning and end-of-life care: A [U.S.] survey of providers' (p.8), in *American Journal of Hospice & Palliative Medicine*.

'End-stage renal disease and hospice care in the U.S.: Are dialysis patients welcome?' (p.8), in *American Journal of Kidney Diseases*.

'Palliative care competencies and readiness for independent practice: A report on the American Academy of Hospice & Palliative Medicine review of the U.S. Medical Licensing Step Examinations' (p.10), *Journal of Pain & Symptom Management*.

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<http://goo.gl/frPgZ5>

Inside the prison hospice where no inmate dies alone

CALIFORNIA | Reuters – 19 June 2018 – One of Fernando Murillo’s greatest fears is dying in prison. The 38-year-old former gang member, serving a sentence of 41 years to life for second-degree murder when he was 16, says it is that fear which helps him empathize with the terminally ill inmates he looks after at a California prison hospice. Murillo’s work in the 17-bed hospice unit at the medium-security California Medical Facility in Vacaville, about 55 miles (88.51 km) northeast of San Francisco, includes helping dying prisoners take a shower or go to the bathroom. But there is another, more important element to the job, he says. “I listen to people’s regrets, their stories, their happiness, their joy. I listen to their confessions,” Murillo says. “I befriend somebody when they’re perfectly healthy, walking around, I’ll take care of them when they’re unable to talk and eventually hold their hands when they’re taking their last breaths.” He and his fellow inmate workers take that work seriously. When someone under their care has 72 hours left to live, they never leave his side. “No prisoner dies alone” is their motto. The hospice, set up during the height of the AIDS crisis in the early 90s, was the nation’s first licensed prison hospice. It now houses more inmates who are dying because of old age diseases, as the over-60 population swells in U.S. prisons, mirroring the aging of the general population. Reuters visited two California prisons recently to look at the challenges states face, as improved medical care, long sentences from tougher crime laws, and a steady increase of older adults entering prison has contributed to an extraordinary rise of elderly inmates. <https://goo.gl/9Fs5ha>

N.B. End-of-life care in the prison system has been high-lighted 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 May 2018) can be downloaded/viewed at: <https://goo.gl/YLckx6>

Hospices taking on a bigger role in the opioid crisis response

HOME HEALTH CARE NEWS | Online – 19 June 2018 – The hospice industry has made it well known it can play a bigger part in addressing the national opioid crisis, but the role of hospices are playing may already be broader than some think. Hospice organizations are frequently acting as a first line of support for families and loved ones of those lost to addiction through bereavement and grief counseling services – and providers aren’t reimbursed for this care. Under the hospice Conditions of Participation (CoPs) to participate in Medicare, providers must offer bereavement services, including counseling. Without reimbursement, how these services are conducted varies widely from organization to organization based on commitments of resources. Many hospices have taken the mission of providing grief counseling and bereavement services one step beyond their own patients, offering this care to families who were not patients, but may have been victims of the opioid crisis. <https://goo.gl/nJsb83>

New report on palliative care finds big increase in services throughout California

CALIFORNIA HEALTH REPORT | Online – 18 June 2018 – More Californians are participating in palliative care (PC) programs, but the need still outpaces the supply, according to a new report. A mapping project just released by the California Healthcare Foundation found significant progress in the number of programs and participants participating in PC services compared to four years ago. The foundation’s report in 2014 found “uneven distribution” of PC services in the state, and only about 25-50% of needs met. But the 2018 report found that inpatient PC capacity for the entire state ranges from 43% to 66% of need and community-based capacity ranges from 33% to 51% of need. Data compiled after the report was written found that there is now at least some PC capability in every California county. The most significant reason for the increase in PC services is the passage of Senate Bill 1004, a law that requires the California Department of Health Care Services to expand community-based PC services to Medi-Cal beneficiaries. Medi-Cal is the state’s low-income health plan; the program is known federally as Medicaid. <https://goo.gl/SJ2YmW>



Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | Associated Press (Sacramento) – 22 June 2018 – ‘**Nearly 400 people used California assisted death law in 2017.**’ California health officials reported that 374 terminally ill people took drugs to end their lives in 2017, the first full year after a law made the option legal. The California Department of Public Health said 577 people received aid-in-dying drugs last year, but not everyone used them. The median age was 74. The figures are more than double those from the first six months after the law went into effect 9 June 2016. In those early months 191 people received life-ending drugs, while 111 people took them and died. <https://goo.gl/8C6U7Z>

International

End-of-life care in New Zealand

Medical students training for end-of-life-care “woeful”

NEW ZEALAND | Radio New Zealand (Wellington) – 18 June 2018 – The palliative care (PC) sector is warning a crisis for New Zealand’s ageing population is imminent as not enough people are being trained in end-of-life care. Ministry of Health data shows in the next 20 years the number of people dying will increase by 50% or 45,000 each year and by 2068 that number will hit 55,000. Palliative medicine specialist Rod MacLeod said students and junior doctors received a “woeful” amount of training. “I think it’s fair to say that in New Zealand the students are only getting a few days out of their five or six year programme with direct exposure to palliative medicine specialists, and quite frankly that’s woeful.” He said other specialities received a disproportionate amount of attention in the curriculum. Lis Latta oversees the PC module at Dunedin School of Medicine. She said the PC

workforce was ageing and while medical students got more training now than they did six years ago, it was still not enough to replace those who would soon retire. “By 2020, 56% of the current palliative medicine specialist workforce is going to be over the age of 65. So that’s compounded by an ageing population which increases the demand for PC services. So we are facing a shortage.” <https://goo.gl/rq5c2F>

Specialist Publications

‘Do medical students expect palliative care will be satisfying?’ (p.10), in *BMJ Supportive & Palliative Care*.

Related

- NEW ZEALAND | *The Otago Daily News* – 20 June 2018 – ‘**Medical schools team up to face palliative care “crisis.”**’ The Universities of Auckland and Otago are working together on a combined palliative care (PC) curriculum as a crisis in the sector looms, a teaching fellow says. A lack of PC specialists is expected to become more of an issue as both New Zealand’s population and current practitioners age. <https://goo.gl/6M6dHz>

Noted in Media Watch 3 April 2017 (#506, p.6):

- NEW ZEALAND | News Talk ZB (Auckland) – 30 March 2017 – ‘**Government looks to prioritise palliative care.**’ The Government’s making assurances palliative care (PC) is one of its health priorities. It comes as a review of the sector recommends major changes and improvements because of a rising demand for PC from the country’s aging population.¹ Statistics show that there will be an over 50% increase in the number of people needing PC over the next 20 years. <https://goo.gl/Ql1Vr1>

1. ‘The Adult Palliative Care Services in New Zealand: Review and Action Plan,’ Ministry of Health, Government of New Zealand, March 2017. **Download/view at:** <https://goo.gl/PT64BW>

N.B. Additional articles on palliative and end-of-life care in New Zealand noted in this issue of Media Watch.

End-of-life care in Northern Ireland

Politicians unite to demand dignity for terminally ill

U.K. (Northern Ireland) | BBC News (Belfast) – 18 June 2018 – Six political parties have signed a letter calling for a fairer definition of terminal illness to be applied in the Personal Independence Payment (PIP) process. The system requires people with a life expectancy of longer than six months to undertake a face-to-face assessment to prove they are terminally ill. They can then face a wait of up to three months for payment. The Democratic Unionist Party, Sinn Féin, the Social Democratic & Labour Party, the Ulster Unionist Party, the Alliance Party, and the Green Party have signed the letter. Politicians described the current system as “cruel, traumatic and lacking in dignity and compassion.” Charities and clinicians say the six-month definition most severely affects patients suffering from non-cancer terminal conditions, such as dementia, for which it can be difficult to predict an accurate life-expectancy. In April, the Scottish government announced there would be no limit set on how long a patient has left to live before their condition was considered “terminal.” Instead medical professionals can use their own judgement to decide whether the illness is terminal, which will allow the patient to be automatically fast-tracked within the benefits system. <https://goo.gl/uEXkUc>

Noted in Media Watch 11 June 2018 (#567, p.4):

- U.K. (Northern Ireland) | *The Belfast Telegraph* – 7 June 2018 – ‘**Current rules on deciding benefits eligibility for terminally ill are unfair and need to be reviewed.**’ Personal Independence Payments (PIP) has special rules for applicants with terminal illnesses, which allow people to access payments quicker and without a face-to-face assessment. However, this avenue is only open to those who have been given a prognosis of six months or less. This restriction is unfairly excluding many people with terminal illnesses. <https://goo.gl/oeGfrX>

More than 800 doctors sign petition for Hazara man to get palliative care in Australia

AUSTRALIA | *The Guardian* (Surry Hills, New South Wales) – 17 June 2018 – Hundreds of doctors have signed a petition calling on the immigration minister, Peter Dutton, to bring a refugee dying of advanced lung cancer to Australia for palliative care (PC). The 63-year-old is being held on Nauru [an island country in Micronesia, northeast of Australia] and is a member of the persecuted Hazara minority in Afghanistan. He has been formally recognised as a refugee. But the Australian Border Force (ABF) told the man, known as Ali, that he could not come to Australia for PC, despite pleas from doctors on Nauru, who say the care there is inadequate. After reading reports by *Guardian* Australia about Ali’s situation, Dr. Sara Townend wrote to Dutton and launched a petition she urged other doctors in Australia to sign. “Australia has accepted this man as a legitimate refugee,” her letter says. “This means Australia is obligated by international conventions to care for his physical and mental health, whether he is on the mainland, or off shore. Nauru is not an appropriate place for this man to die. The ABF tacitly acknowledged

this by offering to transfer him to Taiwan for PC. He requires expertise beyond what is available on Nauru.” Ali has told the ABF he will not go to Taiwan because he has no friends or family there, was concerned there would be no translator from his language, Hazaraghi, and that there would be no one to perform the Shia Muslim rituals after his death. <https://goo.gl/ysQMea>

Dying refugee on Nauru brought to Australia after public outcry

AUSTRALIA (New South Wales) | Special Broadcasting Service (Artarman) – 23 June 2018 – The Australian government has brought a dying asylum seeker from Nauru to Brisbane for palliative care - buckling in the face of growing outrage. The asylum seeker, identified in media reports as a 63-year-old Hazara father named Ali, is believed to have only months or weeks to live as he fights aggressive lung cancer. The Hazara are a persecuted ethnic group from Afghanistan. <https://goo.gl/YNLNmf>

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Noted in Media Watch 14 May 2018 (#563, p.6):

- **HUMANITARIAN HEALTH DIGEST** | Online – Accessed 11 May 2018 – ‘**It’s about time for palliative care in humanitarian emergencies.**’ The Syrian crisis has shed light on a myriad of complex issues and gaps, many relating to the protracted nature of conflict and displacement outside of camp settings in middle-income countries. The importance of palliative care in such contexts is critical, but rarely discussed, never mind addressed.¹ **Full text:** <https://goo.gl/DZUKxX>

1. ‘The role of palliative care in addressing the health needs of Syrian refugees in Jordan,’ *Medicine, Conflict & Survival*, 2018;34(1):19-38. **Abstract (w. link to references):** <https://goo.gl/uHNYML>

N.B. Additional articles on the provision of palliative care during humanitarian crises or natural disasters noted in the 7 May 2018 issue of Media Watch (#562, p.11).

Who cares for the carer when they’re bereaved?

U.K. | BBC News – 11 June 2018 – There are 6.5 million people in the U.K. caring for sick loved ones. But when their relative dies, the support network often disappears – dealing a double blow to those not only bereaved but who have lost their identity as a carer too. What is it like for them to grieve both? The Department of Health & Social Care says there are millions of registered carers in the U.K. Many receive government support, including Carers Allowance, Carers Credit, tax credits and other benefits, but this often ceases when the cared-for person dies. Caring with Confidence was launched in 2009 as part of the government’s ‘New Deal for Carers’ programme, but funding was cut a year later. Monthly meetings are now held in Solihull, Shropshire, Wolverhampton and Dudley in the West Midlands and South Warwickshire, run voluntarily by the Omega Care for life charity. Independent Age has recently published a report on bereavement, which looks at what the death of a cared-for person means to the carer – from loneliness and isolation, to mental and physical health, financial and practical considerations, and grief.¹ The government said in its recently published Carers Action Plan it would take action to help recently bereaved carers.² <https://goo.gl/tNUhax>

1. ‘Good grief: Older people’s experiences of partner bereavement,’ Independent Age, April 2018. **Download/view at:** <https://goo.gl/hQzkZt>
2. ‘Carers action plan 2018 to 2020,’ Department of Health & Social Care, Government of the U.K., 5 June 2018. **Download/view at:** <https://goo.gl/Wr4wXG>

Noted in Media Watch 30 April 2018 (#561, p.5):

- U.K. (England) | University of Manchester – 24 April 2018 – ‘**Step-change needed in support for carers of terminally ill, argue academics.**’ A new report urges healthcare providers to radically improve the way they support carers of people approaching the end of their life.¹ The report argues a major cultural shift among staff is desperately needed to help carers. Improvements in structures and internal processes are also among the 10 recommendations in the National Institute for Health Research & Hospice UK funded report to improve the way healthcare organisations – such as hospices, hospitals, community nursing and general practice – to support carers’ needs. <https://goo.gl/r76G8q>

1. ‘Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change,’ University of Cambridge & University of Manchester, April 2018. **Download/view at the Hospice UK website:** <https://goo.gl/3UQhAx>

Noted in Media Watch 5 March 2018 (#553, p.5):

- **PALLIATIVE MEDICINE** | Online – 28 February 2018 – ‘**Who cares for the carers at hospital discharge at the end of life?**’ Enabling successful discharge of palliative care patients to home and prevention of readmissions is a key issue for health services. To date, the focus of interventions to achieve this outcome has been on patients. This study shifts the focus of discharge planning to include whether and in what way the support needs of carers might be assessed and addressed during the transition to home care. It offers a new direction for intervention development for hospital discharge to improve support for carers over the transition to home and prevent breakdown of care at home which is often a cause of readmission of patients to hospital. **Full text:** <https://goo.gl/GxLrzV>

Specialist Publications

Connecting personal experiences of loss and professional practices in advance care planning and end-of-life care: A [U.S.] survey of providers

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 21 June 2018 – Although practitioners overwhelmingly agree on the importance of advance care planning (ACP) and preparing for the end of life (EoL), the process is fraught with barriers. The survey sought information from providers in three distinct areas: 1) Personal experiences of loss; 2) Personal ACP; and, 3) Professional practices related to ACP and EoL care. 190 health-care professionals (primarily physicians, nurses, and social workers) participated in the survey across a greater, Metropolitan area in the Midwest. Numerous connections were found between professionals' histories of loss, personal ACP, and professional practices. For example, both clinicians with personal experience caring for someone who is dying and clinicians who had completed their own ACP scored higher in both patient- and family-centered communication and effective care delivery and were more likely to refer patients to hospice and palliative care (PC). Results support educational interventions involving opportunities for reflection and completion and communication about ACP. Additionally,

educational opportunities for students in health care should focus on incorporating both ACP and greater exposure to hospice and PC. **Abstract:** <https://goo.gl/SDMnMS>

Talking about end-of-life care in a timely manner

BREATHE, 2018;13(4):e95-e102. In 2014, a group of physicians of the Catharina Hospital in Eindhoven (in The Netherlands) started a project called 'Talking about end-of-life care in a timely manner.' Just like others in the country, the Eindhoven group noticed that regularly, very frail elderly people were admitted to hospital in acute situations without there ever having been conversations about their wishes concerning treatment options at the end of life (EoL). The project aimed to prevent unnecessary admissions and treatments for these frail patients by stimulating physicians, patients and informal caregivers to start conversations about EoL care together at an earlier stage. **Full text:** <https://goo.gl/h1DQ5U>

N.B. This issue of *Breathe* includes several articles on palliative and end-of-life care. **Journal contents page:** <https://goo.gl/cfpm2i>

Related

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 13 June 2018 – '**Effect of the contents in advance directives on individuals' decision-making.**' The authors randomly presented 185 participants with four distinct types of advance directive (AD): 1) Neutrally framed (as reference); 2) Negatively framed; 3) Religiously framed; and, 4) A combination. Participants were asked which interventions they would like to receive at the end of life. Between 60% and 70% of participants responded "accept the special interventions" on the reference form. However, the majority (70%-90%) chose "refuse the interventions" on the negative form. With respect to the religious form, 70% to 80% chose "not decided yet." Participants who refused special life-sustaining treatments were older, female, and with better prior knowledge about ADs. These findings imply that the specific content of ADs could affect decision-making with regard to various interventions for EoLC. **Abstract:** <https://goo.gl/BgaQkF>

End-stage renal disease and hospice care in the U.S.: Are dialysis patients welcome?

AMERICAN JOURNAL OF KIDNEY DISEASES | Online – 16 June 2018 – Although the dialysis population has changed markedly, hospice has not changed to accommodate dialysis. Hospice is set in its ways, insisting on doing things the way they have always been done. Take it or leave it. And if you take it, many hospice programs will insist that one leaves dialysis therapy. However, the hospice philosophy is but one piece of the puzzle, with the full picture including policy driven by cost. National policy currently restricts access to hospice care to patients with kidney failure who either forego or withdraw from dialysis therapy. An exception is made for patients enrolled in hospice for a different diagnosis for which kidney failure is not thought to be contributing to the 6-month prognosis. In this circumstance, the Medicare

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Beneficiary is eligible for both the Medicare Hospice Benefit and the Medicare end-stage renal disease (ESRD) Benefit to reimburse hospice services and dialysis care, respectively. Patients with ESRD carry a tremendous burden of symptoms and high mortality, but usually die without the benefit of symptom, psychological, and planning support of hospice services. A change in policies governing hospice programs is needed for the lives of patients with kidney failure to end better. **Full text:** <https://goo.gl/j3HyJj>

Noted in Media Watch 11 June 2018 (#567, p.7):

- *HEALTH AFFAIRS* | Online – 4 June 2018 – ‘**Hospice use and end-of-life spending trajectories in Medicare beneficiaries on hemodialysis.**’ Infrequent and late referral to hospice among patients on dialysis likely reflects the impact of a Medicare payment policy that discourages the concurrent receipt of these services, but it may also reflect these patients’ less predictable illness trajectories. Among a national cohort of patients on hemodialysis, the authors identified four distinct spending trajectories during the last year of life that represented markedly different intensities of care. These findings signal the need for greater flexibility in the provision of end-of-life care in this population. **Abstract (inc. list of references):** <https://goo.gl/etf2gM>

Noted in Media Watch 7 May 2018 (#562, p.12):

- *JAMA INTERNAL MEDICINE* | Online – 30 April 2018 – ‘**Association between hospice length of stay, health care utilization, and Medicare costs at the end of life among patients who received maintenance hemodialysis.**’ Patients with end-stage renal disease are less likely to use hospice services than other patients with advanced chronic illness. Overall, 41.5% of hospice enrollees [studied] who had been treated with hemodialysis for their end-stage renal disease entered hospice within three days of death. Although less likely to die in the hospital, and to receive an intensive procedure, these patients were more likely than those not enrolled in hospice to be hospitalized and admitted to the ICU, and they had similar Medicare costs. **Abstract:** <https://goo.gl/pc2kPg>

Informed consent and nudging

BIOETHICS | Online – 19 June 2018 – In order to avoid patient abuse, under normal situations before performing a medical intervention on a patient, a physician must obtain informed consent from that patient, where to give genuine informed consent a patient must be competent, understand her condition, her options and their expected risks and benefits, and must expressly consent to one of those options. However, many patients refrain from the option that their physician believes to be best, and many physicians worry that their patients make irrational healthcare decisions, hindering their ability to provide efficient healthcare for their patients. Some philosophers have proposed a solution to this problem: they advocate that physicians nudge their patients to steer them towards their physician’s preferred option. A nudge is any influence designed to predictably alter a person’s behavior without limiting their options or giving them reasons to act. Proponents of nudging contend that nudges are consistent with obtaining informed consent. The author argues that nudging is incompatible with genuine informed consent, as it violates a physician’s obligation to tell their patients the truth, the whole truth, and nothing but the truth during adequate disclosure. **Abstract:** <https://goo.gl/9ta8fH>

N.B. Additional articles on the ethics of nudging noted in the 2 April 2018 issue of Media Watch (#557, p.12).

[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>



Early and late signs that precede dying among older persons in nursing homes: The multidisciplinary team's perspective

BMC GERIATRICS | Online – 4 June 2018 – It has been found that older persons at nursing homes receive far less palliative care (PC) than younger persons, partly because it is difficult to identify when the final stage of life begins. The teams [i.e., participants at four nursing homes in southern Sweden] working with the older person found it difficult to identify early signs that precede dying mainly because they did not see dying as a process but as a happening, restricted to the last weeks or days of the older person's life. One early sign that the participants identified in different ways among the older persons was resignation, e.g., withdrawal from social contexts, lack of motivation and low mood. Another sign was that the older person developed a need to go through their life, from childhood to the present. Late signs that precede dying were familiar, observed by the staff in everyday practice. The team's collective experience of early and late signs that precede dying constitutes new knowledge that has never been shown in the literature before. This knowledge can increase the understanding of when a PC approach needs to be in place at nursing homes. This approach is relevant to advanced care planning. It would prepare both the staff and the older person for dying and make it possible to conduct person-centered care. Knowledge of ageing, frailty and the dying process in older persons needs to be part of the staff training. Also joint discussions within the organization regarding the preparedness for PC might encourage the managers to facilitate the implementation of a PC approach in nursing homes. **Full text:** <https://goo.gl/EyXcAm>

Noted in Media Watch 19 February 2018 (#551, p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 9 February 2018 – **'Interventions in hospitalised patients with cancer: The importance of impending death awareness.'** The authors examined the number and type of diagnostic and therapeutic interventions in hospitalised patients with cancer in their last days of life. They investigated if physician awareness of impending death affected the use of these interventions. Many patients receive diagnostic and therapeutic interventions in the last days of life of which their advantages are questionable. **Abstract:** <https://goo.gl/TSozvC>

N.B. Additional articles on awareness of imminent or impending death noted in this issue of Media Watch.

Do medical students expect palliative care will be satisfying?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – Accessed 19 June 2018 – During their careers, all doctors will be involved in the care of the dying, and this is likely to increase with current demographic trends. Future doctors need to be well-prepared for this. Little is known about medical students' expectations about providing palliative care (PC). Fifteen U.K. medical schools participated in this study, with 1,898 first and final year students completing an online questionnaire which investigated how satisfying they expect providing PC to be and their attitudes towards PC. At both the beginning and end of their training, a significant proportion of students expect PC to be less satisfying than other care (19.3% first year, 16% final year). Students expecting PC to be less satisfying were more likely to be men, and their attitudes suggest that while they understand the importance of providing PC they are concerned about the potential impact of this kind of work on them personally. Medical student education needs to address not only why PC is important and how to deliver it effectively, but also strategies for dealing positively with the impact of this work on future clinicians. **Abstract:** <https://goo.gl/YdPazW>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 June 2018 – **'Palliative care competencies and readiness for independent practice: A report on the American Academy of Hospice & Palliative Medicine review of the U.S. Medical Licensing Step Examinations.'** Reviewers analyzed 1,090 multiple choice questions and identified 242 (22%) as palliative care (PC) items. PC items were identified in each Step exam. Only 6.6% and 6.2% respectively had end-stage heart disease or multi-morbid illness. Fifty-one percent of PC items addressed ethics (31%) or communication (19.8%), focusing on patient autonomy, surrogate decision makers, or conflict between decision makers. Pain and symptom management was assessed in 28.5% of PC items, and one-third of those addressed addiction or substance use disorder. The authors' findings highlight opportunities to enhance testing of clinical PC skills essential for all licensed physicians practicing medicine. **Abstract (w. link to references):** <https://goo.gl/NDDbLb>

Medicinal cannabinoids in palliative care

BRITISH JOURNAL OF CLINICAL PHARMACOLOGY | Online – 20 June 2018 – There is strong public support for the availability of medicinal cannabis, particularly for people with palliative diagnoses. There are several areas where there is potential for symptom benefits through modulation of the endocannabinoid system, though clinical data to date has been inconclusive in key symptoms such as pain and nausea, and data from other settings such as chemotherapy-induced nausea and vomiting not readily extrapolated. Ideally exploration of medicinal cannabinoids should occur within a clinical trial to accelerate the evidence base to inform practice. In people with refractory symptoms the consideration of unregistered products or off label prescribing should be guided by the potential influences of pharmacokinetic, pharmacodynamic and drug-drug interactions, supported by an informed discussion with the patient, and regular review of net clinical benefit. **Abstract:** <https://goo.gl/Qij7iH>

Noted in Media Watch 7 May 2018 (#562, p.13):

- *JOURNAL OF PSYCHOACTIVE DRUGS* | Online – 1 May 2018 – ‘**Cannabis in end-of-life care: Examining attitudes and practices of palliative care providers.**’ Of interest, cannabis use appears low in palliative care (PC) settings, with few guidelines available to PC providers. Results [of an online survey] demonstrated that PC providers endorse cannabis for a wide range of symptoms, end-of-life care generally, and as an adjuvant medication. Nevertheless, the gap between these beliefs and actual recommendation or prescription appears vast. Many who support the use of cannabis in PC do not recommend it as a treatment. **Abstract:** <https://goo.gl/8AQ1Bp>

Neurological symptoms in palliative care patients

FRONTIERS IN NEUROLOGY | Online – accessed 21 June 2018 – The authors [of this study] found that almost half of the palliative care (PC) patients without a primary neurological disease had neurological symptoms documented in their charts, and 98% of patients in a prospective study reported at least one burdensome neurological/neuropsychological symptom. This is considerably higher than previously described. These findings have an immediate clinical relevance in that significant suffering arises from symptoms which are under diagnosed and therefore insufficiently treated. Some of these symptoms are not well documented in patient charts and may remain undiagnosed and untreated. In addition, the question of withdrawal of life-sustaining treatment is most frequently posed in patients with primary neurological diseases. In consequence, PC teams are confronted on a daily basis with complex neurological questions and burdensome neurologic symptoms. This underscores the importance of the neurological expertise in PC teams. **Full text:** <https://goo.gl/WwhaJ2>

Advance decisions to refuse treatment: What GPs need to know

GP | Online – 19 June 2018 – Since the introduction [in England & Wales] of the Mental Capacity Act 2005 the concept of a living will or advanced directive (AD) has been replaced by an advance decision to refuse treatment. This allows a person to state that a particular treatment should not be carried out or continued if, at a later time and in specified circumstances, the patient lacks capacity to make that decision for themselves. Any AD that was made prior to the Mental Capacity Act coming into force may still be valid under the Act, but no new directives can be made following its introduction. Patients wishing to set out what care they would want, or not want, to receive in the future, will need to make an advance decision. Advance decisions can only be made by a person aged 18 or older and the patient must have the appropriate mental capacity. If you are asked by a patient to assist them in preparing such a decision, you must have assessed capacity and be satisfied the patient has the necessary ability to make the decision. However, the patient must also understand the limitations of any decision they make. Under the advance decision, treatment can be refused except for actions needed to keep a patient comfortable, such as offering food or water by mouth and providing warmth and shelter. A patient can refuse life-sustaining treatment providing this is in writing and signed by them and a witness, whereas other refusals can be made verbally. **Full text:** <https://goo.gl/ziZaXT>

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Noted in Media Watch 4 December 2017 (#541, p.8):

- *EUROPEAN JOURNAL OF HEALTH LAW*, 2017;24(5):523-540. “‘Why should I question a patient’s wish?’ **A comparative study on physicians’ perspectives on their duties to respect advance directives.**’ This article explores factors that impede the implementation of advance directives (ADs) to refuse treatment in three European countries: England, Germany and France. Taking into account socio-cultural and legal aspects, the article shows the extent, to which the law can, and does, influence physicians’ decisions to implement ADs. **Full text:** <https://goo.gl/kXz1u7>

N.B. Selected articles on voluntarily stopping eating and drinking, and the patient’s wish to hasten death, noted in the 11 June 2018 issue of Media Watch (#557, p.10).

Medical futility in concept, culture, and practice

JOURNAL OF CLINICAL ETHICS, 2018;29(2):114-23. This article elucidates the premises and limited meaning of medical futility in order to formulate an ethically meaningful definition of the term, that is, a medical intervention’s inability to deliver the benefit for which it is designed. It uses this definition to show the two ways an intervention could become medically futile, to recommend an even more limited usage of medical futility, and to explain why an intervention need not be futile in order to be withdrawn over patient-based objections. If an intervention retains some benefit, then patients or surrogates might legitimately consider that benefit in their case and request the intervention. Physicians might still be justified in declining it on the grounds that the burdens greatly outweigh the benefits, but not on the grounds of futility. Finally, the article uses bioethics research and healthcare litigation to clarify the meaning of futility in practice and recommends alternative language when possible. **Abstract:** <https://goo.gl/EcaVUN>

Delivery of pediatric cancer care in Mexico: A national survey

JOURNAL OF GLOBAL ONCOLOGY | Online – 12 June 2018 – First, considerable variation exists in annual case volumes, with one third of units treating < 30 patients per year. Second, availability of specialist providers, multidisciplinary tumor boards, and core diagnostic services is greater at medium- and high-volume centers compared with low-volume centers. Third, radiation services and palliative care clinics are only available at 42% and 63% of all centers, respectively. Fourth, one third of centers reported that at least one half of patients are lost to follow-up during the transition from pediatric to adult programs. Finally, commonly reported barriers to delivery of care relate to administration, patient socioeconomics, and limited access to specialized diagnostic and therapeutic services. With an 84% response rate, the study findings likely are generalizable to the overall Mexican childhood cancer care system. The 62 centers included in this study reported a total annual case volume of 4,225 patients. Application of the median case volume (50 per year) to the remaining

12 centers suggests approximately 4,825 new cases of pediatric cancer per year in Mexico. **Full text:** <https://goo.gl/E3Tzxx>

Extract from *Journal of Global Oncology* article

Palliative care (PC) services are available at 63% of centers, but not all have palliative medicine physicians. A growing body of literature supports the role of PC in improving patient and caregiver outcomes, including quality of life and even survival. Moreover, the principles of PC can be applied successfully and can be cost-effective, even in resource-limited settings. In 2014, the General Health Council of Mexico declared an obligation to provide PC services to patients in need. Improvement of access to PC will continue to be a focus of the Mexican Association of Pediatric Oncology/Hematology. Despite the high proportion of centers that lack access to onsite PC and radiation oncology services, these were not commonly reported as major barriers to care; thus, centers without these critical services possibly have relatively good access to PC at nearby institutions.

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Noted in Media Watch 3 November 2014 (#382, p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 October 2014 – ‘**Assessing need for palliative care services for children in Mexico.**’ The authors assess the need for palliative and end-of-life care for children dying in public hospitals affiliated with Ministry of Health in Mexico. A large proportion of pediatric deaths are associated with complex chronic conditions indicating the provision of adequate funding for professional education and palliative care initiatives for children in Mexico should be a topic of the national health care agenda. **Full text (access via ResearchGate):** <https://goo.gl/aDBJxD>

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 19 June 2018 – ‘**A descriptive study of decision-making conversations during pediatric intensive care unit family conferences.**’ Decision-making (DM) involved the following modified stages: information exchange; information-oriented deliberation; plan-oriented deliberation; and determining a plan. Conversations progressed through stages in a non-linear manner. For the main decision discussed, all conferences included a presentation of the clinical issues, treatment alternatives, and uncertainty. A minority of family conferences (FCs) included assessing the family’s understanding (21%), assessing the family’s need for input from others (28%), exploring the family’s desired decision-making role (35%), and eliciting the family’s opinion (42%). **Abstract:** <https://goo.gl/H3MbXF>

N.B. Additional articles on family conferences in the context of palliative and end-of-life care noted in the 12 February 2018 issue of Media Watch (#550, p.13).

Ambulatory advanced cancer patients’ and oncologists’ estimates of life expectancy are associated with patient psychological characteristics but not chemotherapy use

JOURNAL OF PALLIATIVE MEDICINE | Online – 15 June 2018 – Patients with advanced cancer often face distressing decisions about chemotherapy. There are conflicting data on the relationships among perceived prognosis, psychological characteristics, and chemotherapy use, which impair the refinement of decision support interventions. In this study, there were no significant associations between life-expectancy estimates and chemotherapy use nor patient anxiety, depression, hope, or optimism and chemotherapy use. Patients’ life-expectancy estimates for 12 months and oncologists’ for 6 months were associated with higher patient anxiety and depression. Finally, both oncologist and patient estimates of life-expectancy for 6 and 12 months were associated with increased levels of trait hope. These findings highlight the need for interventions to support both patients and oncologists as they clarify prognostic expectations and patients cope with the psychological distress of a limited life-expectancy. **Abstract:** <https://goo.gl/TV2y1c>

Barriers to end-of-life care for LGBT persons in the absence of legal marriage or adequate legal documentation

LGBT NEWS | Online – 19 June 2018 – The experiences of lesbian, gay, bisexual and transgender (LGBT) persons during end-of-life care (EoLC) remain understudied. Given the health disparities and barriers to care experienced throughout the life course of LGBT persons, the frequent involvement of legal spouses in EoLC, and the recency of marriage equality, it can be surmised that LGBT persons might experience significantly different barriers to their desired EoLC compared to their heterosexual and cisgender counterparts. This article aims to synthesize what is known about these barriers, particularly in the absence of legal marriage or protective legal documentation. Of two hundred and twelve articles reviewed, twenty-three were included for analysis. Common barriers that emerged were discriminatory laws (e.g., prohibitions against same-sex marriage) and policies, lack of decision-making capacity, lack of knowledge regarding patient wishes, lack of visitation rights, challenges from biological next of kin, and discrimination and psychological distress. Recommendations for future research are provided based on

Cont.

Gaps that were identified. These include increased research on transgender persons and bisexual persons, and on providers of EoLC. In addition, the recommendations take into account that important legislative and policy changes occurred after the period in which the studies reviewed here were published. The impact of those changes cannot be reported in this study and should be determined by future studies. This synthesis provides the contextual understanding necessary for research and improvement in this vastly understudied area. **Abstract:** <https://goo.gl/9DRbau>

N.B. Additional articles on end-of-life care for LGBT persons noted in the 26 March 2018 issue of Media Watch (#556, p. 3 & p.15):

Related

- POPULATION RESEARCH CENTER RESEARCH BRIEF | Online – Accessed 19 June 2018 – ‘**Same-sex couples devote more attention to end-of-life plans than heterosexual couple.**’ Two key motivators explain this difference: 1) Weaker legal protections for same-sex relationships (Greater engagement in end of life (EoL) planning among gay and lesbian couples has been largely motivated by the weaker legal protections around same-sex relationships, especially prior to legalization of same-sex marriage across the U.S.) and, 2) Concerns about family interference and a lack of family support (Same-sex couples – especially lesbian couples – expressed concerns about family interference and about a lack of support from extended family at the EoL. Heterosexual couples were largely unconcerned about the potential for extended family going against their EoL wishes. Therefore, heterosexual couples may be unprepared if they do encounter family interference.) **Full text:** <https://goo.gl/SSJ6Gd>

The effects of the interventions on the DNR designation among cancer patients: A systematic review

PALLIATIVE & SUPPORTIVE CARE | Online – 18 June 2018 – Fourteen studies with a total of 7,180 participants were included in this review. There were 78.6% (11 of 14) studies that indicated that the interventions could improve the DNR designation rates. Three types of DNR interventions were identified in this review: palliative care (PC) unit service, palliative consultation services, and patient-physician communication program. The significant increases of the time between DNR designation and death only occurred in a patient-physician communication program. The PC unit service provided a continuing care model to reduce unnecessary utilization of healthcare service. The palliative consultation service is a new care model to meet the needs of cancer patients in non-PC unit. The shared decision-making communication program and physician’s compassion attitudes facilitate to make DNR decision early. The individualized DNR program needs to be developed according to the needs of cancer patients. **Abstract (inc. list of references):** <https://goo.gl/S7eyGf>

Related

- *BMC MEDICAL ETHICS* | Online – 19 June 2018 – ‘**Ethical competence in DNR decisions: A qualitative study of Swedish physicians and nurses working in hematology and oncology care.**’ The respondents in this study reflected ethically on their work, and if they deviated from guidelines in relation to DNR decisions, they did so after thorough ethical consideration. However, they also described how the workplace needed to create opportunities for reflection on and discussion of ethics in end-of-life care in oncology and hematology, in order to keep contextual ethical competence on a high level. **Full text:** <https://goo.gl/GEShn6>
- *PEDIATRICS* | Online – 21 June 2018 – ‘**When a mother changes her mind about a DNR.**’ Generally, wide latitude is granted to parents when making decisions for their child on the basis of the wide acceptance of the special relationship between parent and child and the important role played by parents in the lives of children. However, when high-risk decisions are made, health care teams serve as an important societal safeguard that questions whether a parent is an appropriate decision-maker for their child. The authors present an ethical decision-making framework for such cases and examine the impact of barriers and unconscious bias that can exclude parents from their rightful role in directing care for their child. **Abstract:** <https://goo.gl/WfHVaf>

Home-based palliative care program relieves chronic pain in Kerala, India: Success realized through patient, family narratives

THE PERMANENTE JOURNAL, 2018;22(2):17-151. An estimated 1.5 billion people across the globe live with chronic pain, and an estimated 61 million people worldwide experience unrelieved serious health-related suffering. One-sixth of the global population lives in India, where approximately 10 million people endure unrelieved serious health-related suffering. The state of Kerala is home to Pallium India, one of the most sophisticated palliative care (PC) programs in the country. This private organization in Trivandrum provides palliative and hospice care to under-resourced populations and emphasizes holistic pain treatment. The current project features the pain stories of six patients who received treatment from Pallium India. Basic patient demographic information was collected, and a Pallium India staff member who was fluent in Malayalam and English asked questions about each patient's pain experience. Pain narratives illustrate the substantial impact of Pallium India's home visit program and the role of total pain assessment in delivering high-quality PC. **Full text:** <https://goo.gl/MRt6xC>

“A palliative end-stage COPD patient does not exist”: A qualitative study of barriers to and facilitators for early integration of palliative home care for end-stage COPD

PRIMARY CARE RESPIRATORY MEDICINE | Online – 20 June 2018 – Early integration of palliative home care (PHC) might positively affect people with chronic obstructive pulmonary disease (COPD). However, PHC as a holistic approach is not well integrated in clinical practice at the end-stage COPD. General practitioners (GPs) and community nurses (CNs) are highly involved in primary and home care and could provide valuable perspectives about barriers to and facilitators for early integrated PHC in end-stage COPD. Barriers were related to the unpredictability of COPD, a lack of disease insight and resistance towards care of the patient, lack of cooperation and experience with PHC for professional caregivers, lack of education about early integrated PHC, insufficient continuity of care from hospital to home, and lack of communication about PHC between professional caregivers and with end-stage COPD patients. Facilitators were the use of trigger moments for early integrating PHC, such as after a hospital admission or when an end-stage COPD patient becomes oxygen-dependent or housebound, positive attitudes towards PHC in informal caregivers, more focus on early integration of PHC in professional caregivers' education, implementing advance care planning in healthcare and PHC systems, and enhancing communication about care and PHC. **Full Text:** <https://goo.gl/w2nWSW>

N.B. Additional articles on palliative and end-of-life care for people living with COPD noted in the 18 June 2018 issue of Media Watch (#568, p.6).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH* | Online – 15 June 2018 – ‘**Taking one's own life in hospital? Patients and health care professionals *vis-à-vis* the tension between assisted suicide and suicide prevention in Switzerland.**’ In Switzerland, the practice of lay right-to-die societies (RTDS) organizing assisted suicide (AS) is tolerated by the state. Patient counseling and accompaniment into the dying process is overtaken by RTDS lay members, while the role of physicians may be restricted to prescribing the mortal dose after a more or less rigorous exploration of the patient's decisional capacity. However, Swiss health care facilities and professionals are committed to providing suicide prevention. Despite the liberal attitude in society, the legitimacy of organized AS is ethically questioned. How can health professionals be supported in their moral uncertainty when confronted with patient wishes for suicide? As an approach towards reaching this objective, two ethics policies were developed at the Basel University Hospital to offer orientation in addressing twofold and divergent duties: handling requests for AS and caring for patients with suicidal thoughts or after a suicide attempt. Both institutional policies mirror the clash of values and suggest consistent ways to meet the challenges: respect and tolerance regarding a patient's wish for AS on the one hand, and the determination to offer help and prevent harm by practicing suicide prevention on the other. The authors offer an interdisciplinary theoretical reflection with practical illustration. **Full text:** <https://goo.gl/KKuvdU>

Journal Watch

The *British Medical Journal's* patient review initiative: A novel expansion of peer review

THE SCHOLARLY KITCHEN (Blog) | Online – 19 June 2018 – An interesting experiment has been going on for a half-decade, yet isn't front and center in conversations about peer review innovation. This is *The British Medical Journal's* approach to inviting patients and caregivers (called “carers” here) dealing with particular health conditions to review relevant manuscripts. The paradigm shift this represents strikes me as significant – searching for an image for this post showed that nearly all the doctor-patient relationships portray physicians talking (often, literally talking down) to patients, as the experts. But patients with health conditions and their caregivers often become experts in their own right, visiting specialists, hearing differing opinions, learning the ins and outs of coping with chronic or acute conditions, and holding their own insights into what it's like to actually experience a cancer, a heart condition, diabetes, mental illness, or surgery. **Full text:** <https://goo.gl/W5CiDW>

An analysis of discontinued journals by Scopus

SCIENTOMETRICS | Online – 14 June 2018 – Researchers continually strive to communicate their findings to peers, hoping to receive recognition for their contribution in a not-so-distant future. The prevailing idea of “publish or perish” becomes imperative when researchers are applying for competitive grants or academic promotions. Choosing a suitable journal has become an important issue as thousands of journals are available. One of the aspects considered by researchers is the journal's indexation status. Scopus continuously evaluates journals submitted by publishers for indexation, and later, to verify if quality is maintained. During this re-evaluation process, some publication concerns may be raised at journal or publisher level. Consequently, Scopus periodically issues a list of discontinued journals. However, not all journals update their websites in order to inform readers that they have been discontinued. This study shows that 56 journals that were discontinued in 2016 currently affirm on their websites that they are indexed by Scopus. In addition, another 20 journals discontinued in 2016, which do not specifically state that they are indexed by Scopus, include a widget from SCImago that may generate confusion about their current indexing situation. For some journals it seems that the emphasis is placed more on the publishing end of the business than the dissemination of research findings. This study shows that regular updates are among the responsibilities that editorial teams must maintain to ensure the quality and accuracy of the information posted on journal websites. **Abstract (w. list of references):** <https://goo.gl/aBx99g>

New to Media Watch



Pallium, a Dutch-language journal published by Springer, “follows the medical and nursing developments in the field of palliative care” in The Netherlands and Flanders. **Journal home page:** <https://goo.gl/3BpLej>

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.

Cont.

Distribution

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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.

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[Scroll down to 'Media Watch by Barry Ashpole'; 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']

Australia

PALLIATIVE CARE WESTERN AUSTRALIA: <https://goo.gl/fCzNTL>

[Scroll down to 'International Websites']

Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: <https://goo.gl/qw5ti8>

[Click on 'National Resources,' scroll down to 'Palliative Care Network Community']



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

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

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

[Scroll down to 'Additional Resources']

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

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

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

SASKATCHEWAN | Saskatchewan Medical Association: <https://goo.gl/5cftPV>

[Scroll down to 'Palliative Care Network Community']

Europe



EUROPEAN JOURNAL OF PALLIATIVE CARE: <https://goo.gl/KjrR6F>

[March/April 2018 issue (Scroll down to 'The homeless: A vulnerable population with poor access to palliative care.')]

HUNGARY | Magyar Hospice Alapítvány: <https://goo.gl/L7D2hw>

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

South America



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

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