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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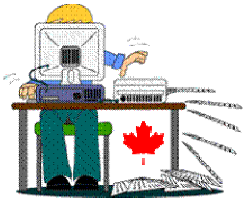

Compiled & Annotated by Barry R. Ashpole

Commonality between palliative and curative medicine: Scroll down to Special Publications and 'Leadership in palliative medicine: Moral, ethical and educational' (p.5), in *BMC Medical Ethics*.

Canada

Another side of opioid crisis: Stigma affecting palliative care patients accessing fentanyl

BRITISH COLUMBIA | CTV News (Vancouver) – 8 June 2018 – Fentanyl has been blamed for thousands of lives lost in British Columbia alone, but there's an unintended consequence of public awareness of the issue. The people who legitimately need the powerful painkillers may not be getting them when they need them most – including during the painful final stages of a terminal illness. End-of-life care can include dealing with the intense physical pain, nausea, shortness of breath and other complications that can come with terminal illness. But some families, and even patients themselves, are turning down painkilling opioids like fentanyl. "It's not a hard sell to (eventually) convince a person in pain that they would like to get rid of this… and usually not for family members. But family members also tend to worry more about things like addiction and something going wrong," palliative care physician Romayne Gallagher said. Doctors like Gallagher point to public confusion about fentanyl, based on what people hear about illicit use and street drugs. Before fentanyl started making headlines, people might ask whether a medication was safe and their doctor would explain risks and benefits, Gallagher said. "But when you're hearing constantly in the news about people dying on the street and it appears they're dying from the very same drugs your doctor wants to give you, it's not surprising people were and continue to be confused about these medications," she said. https://goo.gl/8wSNnb

Specialist Publications

'Not another consultation process: A critique of the implementation of Bill C-277 Framework on Palliative Care in Canada' (p.6), in *Canadian Medical Association Journal*.

'Reflections on the implementation of screening for distress (sixth vital sign) in Canada: Key lessons learned' (p.15), in *Supportive Care in Cancer*.

'Medical assistance in dying in Québec and Canada: Legislative context and implementation issues' (p.16), in *Gaceta Sanitaria*.

N.B. The Government of Canada website on medical assistance in dying (MAiD) was modified 30 May 2018. Content includes: 1) About MAiD; 2) Eligibility criteria; 3) Obtaining MAiD; 4) Roles of the provinces and territories; 5) Independent reviews; 6) Monitoring and reporting on MAiD; and, 7) Supporting palliative care and other end-of-life care option. **Download/view at:** https://goo.gl/R3KHeP

Cont.

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

U.S.A.

Guantánamo commanders make pitch for new prison with hospice-care wing for ex-CIA captives

GUANTÁNAMO BAY NAVY BASE (Cuba) | *The Miami Herald* – 6 June 2018 – The U.S. military's mission at Guantánamo is shifting to permanent detention for al-Qaida and other war-on-terror detainees, commanders told reporters in a rare public pitch for Congress to fund a new $69 million, wheelchair-accessible prison – complete with a hospice-care cellblock – for the five accused 9/11 plotters and 10 other captives... "Picture in your mind elderly detainees, brothers taking care of one another. That is the humane way ahead," said prison spokeswoman Navy Commander Anne Leanos. Guantánamo detention center leaders said that they are shifting their mission because President Donald Trump's January executive order canceled President Barack Obama's mandate to close the prison. https://goo.gl/kjS3cb

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 can be downloaded/viewed at: https://goo.gl/YLckx6

The "right-to-try" law says yes, the drug company says no

THE WALL STREET JOURNAL | Online – 6 June 2018 – Doctors diagnosed Radha Rangarajan in April with late-infantile metachromatic leukodystrophy (MLD), a rare genetic disease that progressively destroys the body's brain, spinal cord and peripheral nervous system, leaving children eventually unable to move or talk. It's rare for anyone with it to live beyond age 10. There are no available treatments designed for the disease, though several are in development. In May, Radha's doctor applied to Shire PLC – an Ireland-based biopharmaceutical company focused on rare diseases. The request: for "compassionate use" of an enzyme replacement therapy that has been tested on a small number of children with MLD in an early clinical trial. Shire denied the request a day later, and again on appeal. The "right-to-try" law that President Donald Trump signed in late May aims to help patients with life-threatening conditions get faster access to investigational drugs by bypassing the Food & Drug Administration's normal approval process. But experts say the law will change little: The FDA already overwhelmingly approved such requests. Drug companies have always made the final call. Arthur Caplan, head of medical ethics at New York University School of Medicine, says Radha's family "is no better off today with right-to-try than it was yesterday." Dr. Caplan ... says drug companies generally prefer the structure of Food & Drug Administration approval, even if they have more freedom to circumvent it now. https://goo.gl/h2Q8sR

Specialist Publications

'Expanding patient access to investigational drugs: Single patient investigational new drug and the "right-to-try"' (p.12), in *Journal of the American College of Cardiology: Basic to Translational Science*.

'False hope with the Right-to-Try Act' (p.12), in *The Lancet*.

N.B. Selected articles on the issue of "right-to-try" new investigational drugs noted in the 4 June 2018 issue of Media Watch (#566, pp.2-3).

Doctors scrutinize overtreatment, as cancer death rates decline

NATIONAL PUBLIC RADIO | Online – 5 June 2018 – Cancer death rates have been falling in recent decades, and that's allowed researchers to ask the important question: "Are some people getting too much treatment for their cancers?" The answer, from the American Society of Clinical Oncology (ASCO) ... is an emphatic yes. Why are doctors giving patients challenging and unnecessary treatments? Dr. Bruce Johnson, president of ASCO and a cancer doctor at the Dana Farber Cancer Institute in Boston, says one reason is that the way that cancer treatments evolve. In the case of breast cancer, the chemotherapy was first developed to treat advanced cancers. There, it was used aggressively to kill as much cancer as possible. Over the years, doctors started using it for less advanced cases, and eventually as a treatment to prevent cancer from coming back (known as "adjuvant therapy"). Doctors and patients already knew that it provided relatively little advantage for many women when used as an adjuvant – perhaps reducing the risk of cancer recurrence by just a few percentage points, for women who have a low risk on genetic tests that can help predict the odds of a recurrence. But narrowing down that risk even more required a huge study, involving 10,000 women and taking many years. Drug companies, which fund many cancer studies, would have no interest in funding that study, so the National Institutes of Health backed it, with the help of governments overseas and advocacy organizations within the U.S. There may be many other cancer treatments that are unneeded and possibly even harmful. Many long-time medical practices are based on tradition and thin evidence. https://goo.gl/FiociF

Specialist Publications

'Hospice use and end-of-life spending trajectories in Medicare beneficiaries on hemodialysis' (p.8), in *Health Affairs*.

'2017 hospice and home health Medicare utilization trends' (p.8), in *Home Health Care News*.

'Economics of palliative care for hospitalized adults with serious illness: A meta-analysis' (p.9), in *JAMA Internal Medicine*.

International

Hospice referrals: North of England gives shortest time

U.K. (England, Scotland & Wales) | BBC News (London) – 7 June 2018 – Terminally ill patients in the north of England get the least amount of end-of-life hospice care in the country, a report claims.[1] On average, patients in the North were referred to hospices 35 days before death compared to 55 days in the South, Midlands and East of England. Co-author Mike Bennett said northern doctors and "stoic" patients may be reluctant to make or accept referrals. Researchers from the University of Leeds and palliative care (PC) charity Hospice UK said some adults with incurable conditions including dementia, liver failure and stroke were not receiving PC from hospices early enough. According to previous clinical trial research, patients with progressive diseases should be referred for PC between three and six months before they die to benefit fully. However, hospices have limited control over the referrals they receive from other health services, which can lead to patients being referred late or not at all, the report said. https://goo.gl/qoDsGx

Extract from Leeds Institute of Health Sciences study

U.K. hospices continue to offer a "last weeks of life" service to predominantly adult patients with cancer, with more than half of all referrals occurring in the last 7 weeks of life (median time 48 days) and 40% occurring within 30 days of death. Inequities in access to hospice-based palliative care (PC) persist; those with non-cancer conditions and older age groups receive a much shorter duration of PC prior to death.

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1. 'Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study,' *Palliative Medicine*, published online 6 June 2018. **Full text:** https://goo.gl/ZXBuwk

Cont.

Related

- U.K. (England) | *The Daily Mail* (London) – 7 June 2018 – **'Dying cancer patients get better hospice care than those with dementia or Parkinson's, finds study that also reveals the young receive more treatment.'** Patients with progressive and incurable diseases like dementia, liver failure, Parkinson's and strokes typically spend around half as much time receiving end-of-life care (EoLC) in hospices than patients with cancer. Leeds University researchers analysed information about 42,000 deaths in the U.K. in 2015 and found patients with cancer were typically referred to hospices 53 days before their deaths, compared to 27 days for other terminal patients. Other inequalities in EoLC included younger people receiving more treatment than older patients, and southerners typically getting more care than northerners. https://goo.gl/GzznDM

Current rules [in Northern Ireland] on deciding benefits eligibility for terminally ill are unfair and need to be reviewed

U.K. (Northern Ireland) | *The Belfast Telegraph* – 7 June 2018 – 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. Over 90% of people accessing PIP via the terminal illness rules have cancer, despite the condition accounting for less than a third of deaths in Northern Ireland. This is largely because cancer has a more easily defined disease trajectory and it is easier to predict when someone is in the last six months of life, giving clinicians more confidence to sign off the benefit forms. Many other terminal illnesses have more unpredictable trajectories and life expectancy is harder to predict accurately. Many terminally ill people, including those with Motor Neurone Disease, chronic heart failure and COPD, fail to access PIP under the special rules, meaning they have to wait much longer for their payments and undergo face-to-face assessments. This is unfair and denies people the best quality of life during the time they have left. The Scottish government has adopted a definition of terminal illness based on clinical judgment, rather than a time-bound estimation of life expectancy. The situation should also be reviewed in Northern Ireland with a view to aligning with the Scottish approach. https://goo.gl/oeGfrX

Changing face of death: Coffin clubs, death midwives and corpses in pyjamas

NEW ZEALAND | *The New Zealand Herald* (Auckland) – 6 June 2018 – Dying used to be a typically brief process. Up until our most recent history, if you survived childhood illness, childbirth, plagues and famine, you generally got sick and then you died – often just days or weeks later. In the absence of today's scans, tests, and life-prolonging drugs, by the time a person was really feeling poorly, their disease was advanced and they succumbed quickly. People died at home, families cared for the body, death was common. Thanks to advances in modern science and economic growth, we are living longer than ever. In New Zealand, a female born in 1906 could expect to live till 66. Fast forward 100 years and a baby girl born in 2016 gained another 27 years, with a life expectancy of nearly 93. Now, for the majority of us the end comes after a long medical struggle (cancer and cardiovascular disease are our two biggest causes of death) or the combined debilities of very old age. With a long life can come a long death, and over time we have unwittingly turned aging and dying into a medical experience. Our final stages have become largely obscured – even to ourselves – as we delegate death to the "professionals." The entire process is outsourced, sanitised and distant. As a result, we have become increasingly unfamiliar with death and consequently more frightened of it... https://goo.gl/nzdfBH

Specialist Publications

'A rights-based proposal for managing faith-based values and expectations of migrants at end-of-life illustrated by an empirical study involving South Asians in the U.K.' (p.14), in *Bioethics*.

'Residential aged care residents and components of end of life care in an Australian hospital' (p.6), in *BMC Palliative Care*.

'Pediatric patients receiving specialized palliative home care according to German law: A prospective multicenter cohort study' (p.7), in *Children*.

Strategic Commissioning of Palliative & End of Life Care by Integration Authorities

U.K. (Scotland) | Scottish Government (Health & Social Care Integration) – Accessed 4 June 2018 – In December 2015, the Scottish Government published the 'Strategic Framework for Action on Palliative & End-of-Life Care,' which set out the aim that by 2021 everyone in Scotland who needs palliative care will have access to it.[1] The Framework includes outcomes and ten commitments to support improvements in the delivery of palliative and end-of-life care (P&EoLC) across Scotland. The second of these reads "We will provide guidance to support Health & Social Care Partnerships with the development of the content of their Strategic Commissioning plans in relation to P&EoLC services." This advice note meets this commitment. **Download/view at:** https://goo.gl/5J7vNK

1. 'Strategic Framework for Action on Palliative & End-of-Life Care: 2016-2021,' Scottish Government, December 2015. [Noted in the 21 December 2015 issue of Media Watch (#441, p.8)] **Download/view at:** http://goo.gl/CKePjU

Specialist Publications

Systematic review for the quality of end-of-life care for patients with dementia in the hospital setting

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 5 June 2018 – The literature reflects a growing awareness of the need to consider a palliative approach to end-of-life (EoL) care for patients with dementia in hospital. Patients with dementia are less likely to receive aggressive care at the EoL, but provision of palliative care interventions is inconsistent. Health-care professionals highlighted the need for greater education around identification and management of problematic symptoms at the EoL. Engagement of family caregivers is essential in optimizing EoL care, and further research is required to ascertain their experiences around decision-making. **Abstract:** https://goo.gl/aUAHfY

N.B. Additional articles on palliative and end-of-life care for people living with Alzheimer's and other forms of dementia noted in the 4 June 2018 issue of Media Watch (#566, pp.13-14).

Leadership in palliative medicine: Moral, ethical and educational

BMC MEDICAL ETHICS | Online – 5 June 2018 – Whilst palliative medicine – and palliative care (PC) more generally - differs from medical practice it is, nevertheless, part of this broader enterprise. As such we should understand its morality or ethos to be an instantiation or realisation of the ethos of medicine. Adopting this point of view we can appreciate that the values, norms and principles that come to the fore in both palliative medicine and PC are not absent from medical practice more generally. It is merely the case that each has a different emphasis. Some of the values, norms and principles that we find in the forefront of curative medical practices do not receive the same emphasis in palliative contexts. There is then, a certain degree of commonality between palliative and curative medicine, as a result there should be room for an appreciation of the shared aspects of their respective ethos. Nevertheless, one should acknowledge that PC is a subaltern medical culture. Whilst this may cause it to be somewhat neglected, or to be relegated to "Cinderella" status, this does provide its practitioners with opportunity for moral, ethical and educational leaderships. Particularly in the context of an aging population, and increasing levels of chronic, and often terminal, illnesses amongst that population, it is becoming increasingly clear that what PC has to offer is what many patients require. Furthermore, at its best, PC can both improve patient's quality of life and its quantity or length. Whilst any number of editorials and OpEd pieces can state these claims, the best proof is to be found by demonstrating the benefits of PC; displaying the contribution PC can make to patients is the best route to being involved in the orchestration of treatment more generally. Over the past few decades PC has established itself as a legitimate medical speciality. The challenge it now faces is to maintain this status whilst also become embedded in, or available to, medical practice more generally. One route to meeting this challenge is through providing the moral, ethical and educational leadership considered above. **Full text:** https://goo.gl/LAVDe9

Residential aged care residents and components of end-of-life care in an Australian hospital

BMC PALLIATIVE CARE | Online – 9 June 2018 – Decision-making in the care of residential aged care (RAC) residents is often complex and challenging. Resourcing RAC facilities adequately is important, especially for making decisions whether to transfer to hospital. This study reinforces that RAC nurses are mainly making these decisions as general practitioner (GP) and extended care paramedic input were suboptimal. Ways to optimise decision-making may include quality improvement of RAC nurses and policy measures to maximise input from the usual GP. Alternative models to support RAC staff include greater collaboration with emergency staff and Hospital in the Nursing Home. Advance care planning plays an important role in decision-making and this study suggests there may be room for improvement, especially documentation of end of life (EoL) wishes and hospitalisation orders. This study has described the components of EoL care for hospitalised RAC residents. By describing the extent of palliative care required, it is hoped that providers and policy makers in primary care, RAC, ambulance and hospital services have more information to assist with making decisions about what is the most appropriate care for this population. **Full text:** https://goo.gl/iXoPXi

Experiences of older people dying in nursing homes: A narrative systematic review of qualitative studies

BMJ OPEN | Online – 4 June 2018 – The findings of this review highlight numerous significant continuing issues faced by older people dying in nursing and care homes. The challenges, both practical and ethical, to investigating death may well be contributing factors to the limited research available on this important topic. Despite the dearth of relevant studies, this review highlighted the critical value of professional sensitivity to broader psychosocial aspects of older people's dying experience in care homes. Too often investigations have focused on aspects of care that can be more easily measured and delineated by policies and protocols. This research identifies the ongoing need for enhanced professional consciousness of psychological, social and cultural elements inherent within dying. The experience of dying is a complex, multifaceted one, and timing of interventions, including advance care planning, can be critical to the value for dying people. In reviewing the available research, the authors were struck by the many aspects of care and experiences identified that seemed potentially avoidable. The combined findings within this review suggest that much more can and should be done in understanding and supporting older people dying in nursing homes. Perhaps in the future, a more comprehensive picture might be gained by adopting an appreciative enquiry approach focusing on positive experiences and what works well, rather than on negative aspects of older people's experiences. **Full text:** https://goo.gl/Z6gXh1

Not another consultation process: A critique of the implementation of Bill C-277 Framework on Palliative Care in Canada

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 1 June 2018 – Lauren Vogel in her commentary, questioned the necessity of Bill C-277, Framework on Palliative Care in Canada, in light of the federal government's previous funding of the Canadian Hospice Palliative Care Association (CHPCA) in 2013 to develop a national framework on palliative care (PC) – a framework endorsed by all provinces and territories.[1] She added that many Senators questioned the need to redefine PC when there was consensus among health professionals on the current definition. The authors take this commentary one step further to call into question the implementation of this bill, which passed 12 December 2017. The law required that the government initiate a consultation process by 12 June 2018. Health Canada launched this process 16 April 2018, with representation from the Canadian Partnership Against Cancer, CHPCA, Canadian Virtual Hospice, Pallium [Canada], Centre for Palliative Care British Columbia, and Palliative Care Matters. The authors question the necessity of undertaking this process when consultation has been done at the provincial, territorial, and federal levels. This is a duplication of past efforts, and a questionable use of public funds. **Full text:** https://goo.gl/TYiJjW

1. 'Just get on with improving palliative care, plead experts,' *Canadian Medical Association Journal*, 2017; 189(44):E1376. **Full text:** https://goo.gl/8v4Qu5

Cont.

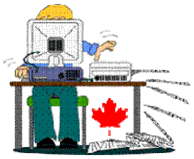
N.B. Articles on the evolution of a national palliative care strategy for Canada noted in the 1 January 2018 issue of Media Watch (#544, pp.18-19). Articles on the passage of Bill C-277 noted in the 18 December 2017 issue of Media Watch (#543, pp.1-2). For a listing of nine key studies on end-of-life care in Canada, published between 1995-2014 see the 22 December 2014 issue of Media Watch (#389, p.4). See also 'Right to Care: Palliative care for all Canadians,' Canadian Cancer Society, December 2015, noted in the 18 January 2016 issue of Media Watch (#445, p.1).

Pediatric patients receiving specialized palliative home care according to German law: A prospective multicenter cohort study

CHILDREN | Online – 31 May 2018 – In Germany, every child with a life-limiting condition suffering from symptoms that cannot sufficiently be controlled is eligible by law for specialized pediatric palliative home care (SPPHC). Patients who are referred to SPPHC teams in Germany are a diverse cohort, often with complex conditions. This complexity is characterized by a large range of differing diagnoses, heterogeneous, and mostly neurologically originating symptoms, and care goals that are focused on prolonging life. To address these goals, teams must be comprised of multiple professionals with different areas of expertise, especially neuro-pediatrics. The small number of pediatric cases limits the possibilities for conducting controlled studies and, therefore, developing evidence-based treatment guidelines. To overcome these difficulties and ensure high quality palliative care for children, each therapeutic measure must be conducted in close collaboration between the relevant pediatric departments. **Full text:** https://goo.gl/af8jG2

The Social Meaning in Life Events Scale (SMILES): A preliminary psychometric evaluation in a bereaved sample

DEATH STUDIES | Online – 5 June 2018 – A mourner's success in making meaning of a loss has proven key in predicting a wide array of bereavement outcomes. However, much of this meaning-making process takes place in an interpersonal framework that is hypothesized to either aid or obstruct this process. To date, a psychometrically validated measure of the degree to which a mourner successfully makes meaning of a loss in a social context has yet to be developed. The present study examines the factor structure, reliability, and validity of a new measure called the Social Meaning in Life Events Scale (SMILES) in a sample of bereaved college students. The SMILES displayed a two-factor structure, with one factor assessing the extent to which a mourner's efforts at making meaning were invalidated (Social Invalidation subscale), and the other assessing the extent to which a mourner's meaning-making process was validated (Social Validation subscale). The subscales displayed good reliability and construct validity in reference to several outcome variables of interest (complicated grief, general health, and post-loss growth), as well as related but different variables (social support and meaning made). The subscales also demonstrated group differences according to two demographic variables associated with complications in the mourning process (age and mode of loss), as well as incremental validity in predicting adverse bereavement outcomes over and above general social support. Clinical and research implications involving the use of this new measure are discussed. **Abstract:** https://goo.gl/hNhjBm



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

Hospice use and end-of-life spending trajectories in Medicare beneficiaries on hemodialysis

HEALTH AFFAIRS | Online – 4 June 2018 – 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. Within the cohort, 9% had escalating spending and 13% had persistently high spending throughout the last year of life, while 41% had relatively low spending with late escalation, and 37% had moderate spending with late escalation. Across the four groups, the percentages of patients enrolled in hospice at the time of death were uniformly low ranging from only 19% of those with persistently high costs to 21% of those with moderate costs and the median number of days spent in hospice during the last year of life was virtually the same (either five or six days). 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

2017 hospice and home health Medicare utilization trends

HOME HEALTH CARE NEWS | Online – 4 June 2018 – Compared to home health care, hospice had significant growth in 2017, with 1.3 million Medicare enrollees – a 6.5% jump from 2016. Almost half – 47.5% – of enrollees were over the age of 84, while only 13% of admissions were for patients younger than 70. This suggests that, 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. More awareness of hospice services may also be causing rise in use among Medicare enrollees. **Full text:** https://goo.gl/9Kq4T4

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.'** Overall, 41.5% of hospice enrollees 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. Without addressing barriers to more timely referral, greater use of hospice may not translate into meaningful changes. **Abstract:** https://goo.gl/pc2kPg

Encountering existential loneliness among older people: Perspectives of health care professionals

INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH & WELL-BEING | Online – 5 June 2018 – Encountering existential loneliness is experienced by health care professionals as both challenging and meaningful, and it is important to talk about it and highlight its role in providing good-quality care to older people. It is demanding for health care professionals to encounter existential loneliness and to discuss issues such as the meaning of life, death, guilt, and regret, which prompt professionals to reflect upon existential aspects of their own lives. Consequently, the effects of facing existential loneliness do not seem to be limited to the caring situation, but rather to affect health care professionals both personally and professionally. Giving health care professionals time to reflect, both with their colleagues and alone, could increase their self-awareness and significantly improve the quality of care for older people in the later phases of their lives. **Full text:** https://goo.gl/s1yNW9

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Noted in Media Watch 26 February 2018 (#552, p.4):

- *RESURGENCE & ECOLOGIST*, 2018, Issue #307. **'Tackling loneliness and isolation reduces health bill.'** A "compassionate community" scheme aimed at tackling the connection between loneliness and ill health has helped cut emergency hospital admissions in its area by 17%, official figures reveal. At a time when hospital overcrowding and the future of the National Health Service are becoming a major political issue in Britain, the small town of Frome in Somerset, south-west England, is bucking the trend with a scheme that may have international implications for health policy. **Full text:** https://goo.gl/68ngwg

N.B. Additional articles on the potential detrimental effect on health of loneliness and isolation noted in the 22 May 2017 issue of Media Watch (#513, pp.3-4). On a related subject, articles on decision-making for "unbefriended" or "unrepresented" patients noted in the 18 September 2017 issue of Media Watch (#530, p.14).

Economics of palliative care for hospitalized adults with serious illness: A meta-analysis

JAMA INTERNAL MEDICINE, 2018;178(6):820-829. What is the estimated association of palliative care (PC) consultation within 3 days of admission with direct hospital costs for adults with serious illness? In this meta-analysis of 6 studies, hospital costs were lower for patients seen by a PC consultation team than for patients who did not receive this care. The estimated association was greater for those with a primary diagnosis of cancer and those with more comorbidities compared with those with a non-cancer diagnosis and those with fewer comorbidities. The estimated association of PC consultation with hospital costs varies according to baseline clinical factors; prioritizing current staff to patients with a high illness burden and increasing capacity may reduce hospital costs for a population with high policy importance. **Abstract:** https://goo.gl/4xwr7F

Related

- *JOURNAL OF CLINICAL PATHWAYS* | Online – 8 June 2018 – **'Are end-of-life care costs actually decreasing?'** It is well documented that health care expenditures are on the rise in the U.S. Recent studies of end-of-life (EoL) practice patterns suggest that increased hospice care costs more than it saves, EoL care intensity continues to increase, and EoL care costs may be accelerating. However, a group of researchers from the Dartmouth Institute for Health Policy & Clinical Practice have found that *per-capita* EoL spending is actually decreasing and contributing to overall *per-capita* Medicare spending growth moderation. Researchers point to changes in both supply and demand factors for this trend. **Full text:** https://goo.gl/AdvABW

The 50-year legacy of the Harvard report on brain death

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 7 June 2018 – History is full of ironies, and the 50-year legacy of the Harvard report is no exception.[1] From one perspective, the report laid the foundation for laws that have both saved and improved the lives of hundreds of thousands of patients through organ and tissue donation. Conversely, decades of attempts to find a conceptual justification for linking this diagnosis to the death of the patient remain incomplete. The significance of brain death may diminish in the near future. If new genetic technologies render xenotransplantation safe, there could be a supply of transplantable organs without resorting to human donors (although the approach would raise its own ethical concerns). Tissue engineering and 3-dimensional printing might yield synthetic organs. Such developments would make the diagnosis of brain death irrelevant for organ procurement. Until then, however, one warning remains apt – Capron, one of the architects of the Uniform Determination of Death Act, summarized the situation well in 2001 when he described efforts to determine when death has occurred as both "well settled, yet still unresolved." **Full text:** https://goo.gl/g6B8X2

1. 'A definition of irreversible coma,' Ad Hoc Committee of the Harvard Medical School, *Journal of the American Medical Association*, 1968;205(6):337-340. **Abstract:** https://goo.gl/hDazg5

Measuring attitudes about end-of-life care: Evaluation of a modified version of the hospice philosophy scale

JOURNAL OF APPLIED GERONTOLOGY | Online – 4 June 2018 – The Hospice Philosophy Scale (HPS) is the only scaled instrument that measures health professionals' attitudes about end-of-life (EoL) care consistent with the hospice philosophy. This study tested the properties of a modified version of the HPS to provide preliminary validation data on internal consistency, convergent validity, and factorability in a broad population of adults. A telephone survey designed to assess the general population's attitudes regarding hospice use was administered. exploratory factor analysis elicited an eight-item instrument (HPS-8). The HPS-8 ... demonstrated sufficient convergent validity, including positive associations with a scale measuring the importance of relevant EoL issues, a personal preference for hospice, and, among those who had experienced hospice care, satisfaction with hospice care. **Abstract:** https://goo.gl/52FhyC

Clinic, courtroom or (specialist) committee: In the best interests of the critically ill child?

JOURNAL OF MEDICAL ETHICS | Online – 7 June 2018 – Law's processes are likely always to be needed when particularly intractable conflicts arise in relation to the care of a critically ill child like Charlie Gard. Recourse to law has its merits, but it also imposes costs, and the courts' decisions about the best interests of such children appear to suffer from uncertainty, unpredictability and insufficiency. The insufficiency arises from the courts' apparent reluctance to enter into the ethical dimensions of such cases. Presuming that such reflection is warranted, this article explores alternatives to the courts, and in particular the merits of specialist ethics support services, which appear to be on the rise in the UK. Such specialist services show promise, as they are less formal and adversarial than the courts and they appear capable of offering expert ethical advice. However, further research is needed into such services – and into generalist ethics support services – in order to gauge whether this is indeed a promising development. **Abstract:** https://goo.gl/Xed1WX

> **N.B.** Additional articles on the Charlie Gard case noted in the 28 May 2018 issue of Media Watch (#565, pp.11-12).

Voluntarily stopping eating and drinking: A practical approach for long-term care facilities

JOURNAL OF PALLIATIVE MEDICINE | Online – 5 June 2018 – Some residents of long-term care (LTC) facilities with lethal or serious chronic illnesses may express a wish to hasten their death by voluntarily stopping eating and drinking (VSED). LTC facility clinicians, administrators, and staff must balance resident safety, moral objections to hastened death, and other concerns with resident rights to autonomy, self-determination, and bodily integrity. Initially, requests for hastened death, including VSED must be treated as opportunities to uncover underlying concerns. After a concerted effort to address root causes of suffering, some residents will continue to request hastened death. Rigorous resident assessment, interdisciplinary care planning, staff training, and clear and complete documentation are mandatory. In addition, an independent second opinion from a consultant with palliative care and/or hospice expertise is indicated to help determine the most appropriate response. When VSED is the only acceptable option to relieve suffering of residents with severe chronic and lethal illnesses, facilitating VSED requests honors resident-centered care. The author offers practice suggestions and a checklist for LTC facilities and staff caring for residents requesting and undergoing VSED. **Abstract:** https://goo.gl/eppFVf

> **N.B.** Selected articles on voluntarily stopping eating and drinking, and the patient's wish to hasten death, noted in the 26 March 2018 issue of Media Watch (#556, p.9).

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.

Cancer patient perspectives regarding preparedness for end-of-life care: A qualitative study

JOURNAL OF PSYCHOSOCIAL ONCOLOGY | Online – 4 June 2018 – Despite growing interest in the concept of "preparedness," however, there is insufficient information about what cancer patients actually need to feel prepared. Such information is foundational for patient-centered care, theory-building, and instrument development. Participants were drawn from a large academic cancer center and had a diverse range of malignancies. Six overarching themes emerged, including readiness to manage concerns about: 1) EoL planning (e.g., goals of care, location of care); 2) Interactions with healthcare providers (e.g., communication, symptom control); 3) Interactions with family/friends (e.g., perceived burden, support); 4) Emotional well-being (e.g., existential distress, fulfillment); 5) Spiritual well-being (e.g., spiritual comfort, congregational support); and, 6) Financial well-being (e.g., medical expenses, estate planning). Participants emphasized broader concerns than those previously construed as facets of patient preparedness, and these domains offer modifiable targets for intervention. **Abstract:** https://goo.gl/XbDuTx

Training community clergy in serious illness: Balancing faith and medicine

JOURNAL OF RELIGION & HEALTH | Online – 6 June 2018 – The objective of this study was used to identify best practices in an end of life (EoL) training program for community clergy. As part of the National Clergy Project on End-of-Life Care, the project conducted key informant interviews and focus groups with active clergy in five U.S. states (California, Illinois, Massachusetts, New York, and Texas). A diverse purposive sample of 35 active clergy representing pre-identified racial, educational, theological, and denominational categories hypothesized to be associated with more intensive utilization of medical care at the EOL. The authors assessed suggested curriculum structure and content for clergy EoL training through interviews and focus groups for the purpose of qualitative analysis. Thematic analysis identified key themes around curriculum structure, curriculum content, and issues of tension. Curriculum structure included ideas for targeting clergy as well as lay congregational leaders and found that clergy were open to combining resources from both religious and health-based institutions. Curriculum content included clergy desires for educational topics such as increasing their medical literacy and reviewing pastoral counseling approaches. Clergy identified challenging barriers to EoL training needing to be openly discussed, including difficulties in collaborating with medical teams, surrounding issues of trust, the role of miracles, and caution of prognostication. **Abstract (inc. list of references):** https://goo.gl/bRXhYc

Exploring the challenges that family caregivers faced when caring for hospice patients with heart failure

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 1 June 2018 – Although patients with heart disease comprise the second largest diagnostic group in hospice care, the challenges faced by family caregivers (FCGs) of hospice patients with heart failure are poorly understood and often go unaddressed. This study explored the challenges and needs of FCGs of adults with advanced heart failure receiving hospice care in the home. The baseline quantitative and qualitative data from 28 FCGs' participation in a large-scale hospice clinical trial of a problem-solving therapy intervention were analyzed. The data showed FCGs were mildly anxious and had worse financial and physical quality of life (QoL) than their social and emotional QoL. The data further showed caregiver challenges were related to patient care and symptom management, inadequate social support, communication issues, and financial concerns. The results provide insight to hospice social workers and researchers to develop practical tools that can be used in routine care to evaluate FCGs' needs... **Abstract:** https://goo.gl/cEUuxH

False hope with the Right-to-Try Act

THE LANCET, 2018;391(10137:2296. Critics – including the American Cancer Society and the American Society of Clinical Oncology, among many others – contend that right-to-try laws add little benefit over the existing Food & Drug administration (FDA) "expanded access/compassionate use" programme (active since the 1970s) that allows applicants to be granted access to experimental drugs and approves applications at a rate greater than 99%. The law also lowers the bar from terminal illness to "a life-threatening illness or condition." Diabetes and heart disease are both life-threatening, but do they justify access to unproven, perhaps harmful or even deadly, experimental drugs? Scott Gottlieb, Trump's FDA commissioner, criticised that change, and it is unclear how the FDA will interpret the new law. Republican Senator Ron Johnson, author of the law, has said bluntly that it is intended to weaken the FDA. Pharmaceutical companies decide who gets access to experimental drugs, and it is not clear the new law would make them any more inclined to accede. The new law offers little benefit in marshalling new drugs through the FDA's approval process. Patients given access to the drugs will be outside randomised controlled trials (RCT). Their data will not advance approval, and any adverse effects they might suffer could potentially damage a drug's approval chances. Patients might also intentionally try to circumvent the RCT system entirely, due to fears of receiving a *placebo*. The Right-to-Try Act removes a barely existent barrier. It is a political gesture, aimed at diminishing the power of the FDA over drug regulation, and intended to force critics to appear to stand between the dying and hope. The changes it offers will do little to help, and might do an unknowable amount of harm. **Full text:** https://goo.gl/n1ZpWG

Related

- *JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY: BASIC TO TRANSLATIONAL SCIENCE*, 2018;3(2):280-293. **'Expanding patient access to investigational drugs: Single patient investigational new drug and the "right-to-try."'** With drug approval times taking an average of 8 years from entry into clinical trials to full Food & Drug Administration (FDA) approval, patients with life-threatening and severely debilitating disease and no reasonable therapeutic options are advocating for expanded access (EA) to investigational drugs prior to approval. Special investigational new drug (IND) application categories allow patients who meet specific criteria to receive treatment with non-approved drugs. The FDA approves over 99% of all single-patient INDs, providing emergency approval within hours, and non-emergency approval within an average of 4 days. "Right-to-try" laws passed in 38 states would allow patients to bypass FDA processes altogether, but contain controversial provisions that some claim risk more harm than benefit to desperate and vulnerable patients. This review focuses on FDA EA to non-approved drugs through a special category of IND – the single-patient IND – and "right-to-try" access outside of the FDA. **Full text:** https://goo.gl/e5ofY1

N.B. The Federal "right-to-try" bill was recently signed into law. Selected articles on the issue of "right-to-try" new investigational drugs noted in the 4 June 2018 issue of Media Watch (#566, pp.2-3).

End-of-life care in France

Doctor-patient relationship and the general practitioner's place in the approach of advance directives: Patients' points of view

MÉDECINE PALLIATIVE | Online – 3 June 2018 – Since 2005, the Leonetti law has allowed any adult to write advance directives (ADs) in the case that they are, one day, unable to express their wishes. Despite this, in 2012, only 2.5% of concerned patients had written ADs. They are, even today, rarely evoked with patients although they are accompanied, throughout the disease, by the general practitioner, the oncologist and the health care team. Thirty-one patients were interviewed and most of them expressed their support for ADs. A precocious approach, at the beginning of serious illness, and personalized seems preferable. Patients are seeking information and support during illness and in their decision-making. They have specific expectations for each practitioner. Despite the small sample, these data show that the doctor-patient relationship conditions the onset of ADs that needs to be personalized. The literature notes

Cont.

that short, repeated and interactive exchanges would allow a higher rate of writing. Nevertheless, the involvement (temporal and emotional) required for doctors can slow down this approach. From this study, three perspectives can be considered: 1) To evaluate the psychological impact of the evocation of the ADs; 2) To evaluate the effectiveness of repeated exchanges on the directives; and, 3) If necessary, to propose an accompaniment in the approach of their writing. **Abstract:** https://goo.gl/3Er88F

N.B. French language article.

Related

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 8 June 2018 – '**Addressing personal barriers to advance care planning: Qualitative investigation of a mindfulness-based intervention for adults with cancer and their family caregivers.**' The Mindfully Optimizing Delivery of End-of-Life (MODEL) Care intervention provided 12 hours of experiential training to two cohorts of six to seven adults with advanced-stage cancer and their family caregivers. Training included mindfulness practices, mindful communication skills development, and information about advance care planning (ACP). Patient and caregiver experiences of the MODEL Care program were assessed using semi-structured interviews administered immediately post-intervention and open-ended survey questions delivered immediately and at 4 weeks post-intervention. **Abstract:** https://goo.gl/P1KKW3

Combining technology and support in palliative care: A reasonable obstinacy?

MÉDECINE PALLIATIVE | Online – 3 June 2018 – The so-called Leonetti law has introduced in France the notion of unreasonable obstinacy. However obstinacy is necessary and often reasonable, it is the base of medical and nursing practice. This is also true in palliative care. Obstinacy to understand what the patient wants, what he presents, what he is living and who he is. Obstinacy to understand who we are as professionals and how we interact with the patient, his family and among ourselves. Obstinacy in knowing and mastering technology, without being blind and considering it all-powerful but not refusing it only because death is natural. Finally obstinacy in research then in making or accepting decisions. These decisions are always uncertain and imperfect but they are the expression of the vitality and the creativity of an interdisciplinary approach to serve the doctor-patient relationship. **Abstract:** https://goo.gl/ggVEUD

N.B. French language article.

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 3 June 2018 – '**Mobile health technology is here – but are hospice informal caregivers receptive?**' In this study, a substantial majority of informal caregivers voiced receptivity to using mHealth apps and expressed interest in features that enhance communication and provide information to improve patient care. Although more research is needed to examine how to incorporate this technology into existing home hospice care, the authors suggest that informal caregivers are likely to use this technology they feel will help enhance home-based end-of-life care delivery. **Abstract:** https://goo.gl/b664yb

Noted in Media Watch 30 April 2018 (#561, p.14):

- *PROGRESS IN PALLIATIVE CARE* | Online – 26 April 2018 – '**Mobile health technology and home hospice care: Promise and pitfalls.**' Hospice care, which is commonly provided at home, may particularly benefit from the use of this technology platform. This commentary outlines several potential benefits and pitfalls of incorporating mobile health applications into existing home hospice care while highlighting some of the relevant telemedicine work being done in the palliative and end-of-life care fields. **Abstract:** https://goo.gl/PRaDSa

  N.B. Additional articles on the pros and cons of mobile health technology in the context of home hospice and palliative care noted in this issue of Media Watch.

End-of-life care in Australia

Culturally and linguistically diverse palliative care patients' journeys at the end-of-life

PALLIATIVE & SUPPORTIVE CARE | Online – 4 June 2018 – This study was conducted at a sub-acute hospital with a specialist palliative care (PC) unit and a community PC service in a metropolitan region of New South Wales, Australia. The most common symptoms burdening the patients were decreased mobility (82%), pain (76%), and poor appetite (60%). The majority of patients (87%) were diagnosed with cancer. Language was a major barrier to the assessment and management of symptoms. The vast majority of patients were born in Europe and Asia. Twenty-nine percent of the patients preferred to use English. However, among patients who required an interpreter on admission, only 9% used professional interpreters. Family distress around patients' lack of food consumption was prominent, along with provider concern when this led to families "force feeding" patients. Only 5% of files documented patients', and 21% of files documented families', cultural wishes or needs. Care of the body after death was only documented in 20% of files. **Abstract (inc. list of references):** https://goo.gl/g3bnNx

Noted in Media Watch 21 May 2018 (#564, p.13):

- *PALLIATIVE MEDICINE* | Online – 16 May 2018 – '**"Death is difficult in any language": A qualitative study of palliative care professionals' experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds.**' The following themes emerged: 1) Determining the rules of engagement around discussion of diagnosis and prognosis; 2) Navigating the challenge of language to patient understanding; 3) Understanding migration experiences to establish trust; 4) Maintaining the balance between patient safety and comfort care; 5) Providing a good death experience through accommodation of beliefs; and, 6) Navigating the important role of family members while privileging patient preferences. **Abstract**: https://goo.gl/ezBDFx

Related

- *BIOETHICS* | Online – 8 June 2018 – '**A rights-based proposal for managing faith-based values and expectations of migrants at end-of-life illustrated by an empirical study involving South Asians in the U.K.**' The authors argue for accommodation of faith-based values of migrants at end-of-life (EoL) within normative structures of receiving countries. They posit ethically relevant principles of inclusiveness, integration and embedment, for an innovative bioethical framework as a vehicle for accommodating faith-based values and needs of migrants at EoL. **Abstracts:** https://goo.gl/AaizKS

- *CLINICAL ETHICS* | Online – 3 June 2018 – '**Truth-telling to a cancer patient about poor prognosis: A clinical case report in cross-cultural communication.**' The author discusses ... the ethical dilemma of truth-telling and withholding information about poor prognosis. It highlights the complexities of applying ethical principles in a different cultural milieu, reflecting on different ethical frameworks and justifications. He also discusses some of the wider implications of the practices, issues and controversies of truth-telling about prognosis in cross-cultural communication relevant to clinical practice. **Abstract:** https://goo.gl/mMyPjk

Exploring knowledge and perceptions of palliative care to inform integration of palliative care education into cystic fibrosis care

PEDIATRIC PULMONOLOGY | Online – 3 June 2018 – While palliative care (PC) is a standard of care in serious illnesses, there are no guidelines for its incorporation into cystic fibrosis (CF) care. Patients with CF, caregivers, and CF care providers may lack knowledge about PC and perceive barriers to integrated care. Ten patients with CF, ten parents, and eight CF care providers participated in this single-center study. Many had minimal knowledge of PC and endorsed the association with end of life as a barrier to PC, but after learning more about PC, thought it could be helpful, and should be introduced earlier. These findings warrant replication in a larger, multisite study to inform PC educational interventions as a step toward consistent integration of PC into routine CF care. **Abstract:** https://goo.gl/h5Susk

Cont.

Noted in Media Watch 8 January 2018 (#545, p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 3 January 2018 – **'Exploring opportunities for primary outpatient palliative care for adults with cystic fibrosis: A mixed-methods study of patients' needs.'** Three main domains of palliative care (PC) needs were identified: 1) To be listened to, feel heard, and be "seen"; 2) Understanding the context around cystic fibrosis (CF) and its trajectory, with the goal of preparing for the future; and, 3) Information about, and potential solutions to, practical and current circumstances that cause stress. Few patients reported talking with their clinician about their wishes for care if they were to become sicker. **Abstract:** https://goo.gl/AtLrRD

Noted in Media Watch 6 November 2017 (#537, p.9):

- *JOURNAL OF CYSTIC FIBROSIS* | Online – 30 October 2017 – **'Defining palliative care in cystic fibrosis: A Delphi study.'** A working group of 36 cystic fibrosis (CF) care providers, researchers, palliative care (PC) providers, quality improvement experts, individuals with CF, and CF caregivers completed a series of questionnaires to rate the value of each of 22 attributes of PC, rank top attributes to construct definitions of PC, and then rate proposed definitions. Many identified overlaps in routine CF care and PC and highlighted the importance of a definition that feels relevant across the lifespan. **Abstract (w. link to references):** https://goo.gl/z4bZmn

N.B. Additional articles on palliative and end-of-life care for people living with cystic fibrosis noted in this issue of Media Watch.

The importance of attending patient funerals

PEDIATRICS PERSPECTIVE | Online – 5 June 2018 – In my career as a pediatrician, I have gone to many funerals. I have cared for 28 children with recessive dystrophic epidermolysis bullosa in both primary care and hospital inpatient settings and attended 12 of their funerals. These funerals celebrated lives that had meaning, that brought great joy as well as heartache to their friends and families, and that made the world a better, more tolerant and understanding place. At two funerals, almost everyone wore pink, the girls' favorite color. At another, almost everyone wore T-shirts with Batman, the boy's favorite superhero. At another, the church was a sea of Bronco orange because of the boy's football passion. At others, we learned about a boy's well-delivered comedy routines, a girl's love of horseback riding (her horse was outside greeting people as they came to the service), and a girl's love of making lasagna. Attending these funerals provided us with a valuable perspective on the lives of chronically ill children with a terminal illness. They also helped us cope with our frustration. Why could we not have done more to alleviate our patients' suffering and delay the deaths of these children? We gained a deeper understanding that these children, despite their terrible disease and suffering, brought enormous joy to their parents and friends. **Introduction:** https://goo.gl/mRKbnj

N.B. Selected articles on the topic of attending patient funerals noted in the 19 September 2016 issue of Media Watch (#480, p.9).

Reflections on the implementation of screening for distress (sixth vital sign) in Canada: Key lessons learned

SUPPORTIVE CARE IN CANCER | Online – 1 June 2018 – Accreditation bodies in the U.S., the U.K., and Europe have mandated that jurisdictions regularly screen patients for distress. While these requirements have been in place for some time, recent reports suggest that facilities still struggle to overcome implementation barriers. In Canada, a Screening for Distress (the sixth vital sign) Initiative was implemented in eight cancer treatment facilities in seven provinces. With national support and coordination from the Canadian Partnership Against Cancer, the initiative's primary goal was to provide timely and appropriate response to cancer patients' distress to improve the patient experience. Patient experience is defined as the sum of an individual's perceptions, expectations and interactions related to his or her health and care throughout the cancer journey. The implementation included the application of evidence-informed tools by trained health care professionals to identify distress, facilitate intervention or referral, and enhance collaboration among health care providers to meet patient needs. **Abstract (inc. list of references):** https://goo.gl/zxXGdr

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *GACETA SANITARIA* | Online – 5 June 2018 – **'Medical assistance in dying in Québec and Canada: Legislative context and implementation issues.'** In this editorial, the authors review the legislative context that brought about the legalization of medical assistance in dying (MAiD) in Canada, and highlight some of the public health questions that remain surrounding the implementation of these legislations. MAiD is now part of the Canadian legal and medical landscape. Preliminary data show that a growing number of Canadians are choosing it as an end-of-life care (EoLC) option. Recent court challenges and the study of specific issues related to eligibility by expert committees might eventually lead the way to even more Canadians being eligible. Continued attention should be paid to the ways these new legislations are being implemented in different regions of Québec and Canada, and how they are shaping EoLC practices. MAiD should not come at the expense of those who are most vulnerable and the impact on the resources dedicated to palliative care should be assessed, especially given that these services were deemed insufficient to meet the demand by those developing the new legislations. **Full text:** https://goo.gl/e9BXcU

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 6 June 2018 – **'An examination of state level personality variation and physician aid in dying legislation.'** The social dialogue and potential controversy surrounding physician aid in dying (PAD) [in the U.S.] may be linked to aggregate differences in state personality profiles. States with PAD legislation tend to be areas where constituents are on average more open minded and experience greater emotional stability. More work is needed to ascertain whether the experiences of receiving and providing end-of-life care may differ across these regions, particularly in relation to conversations around PAD. **Abstract:** https://goo.gl/N3iBCp

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Cont.

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

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