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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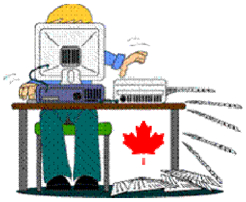

Compiled & Annotated by Barry R. Ashpole

Unprepared bereavement: Scroll down to Specialist Publications and 'Using motivational interviewing to facilitate death talk in end-of-life care: An ethical analysis' (p.8), in *BMC Palliative Care*.

Canada

Evidence suggests that Canadian physicians are not being adequately trained in palliative care

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS | Online – Accessed 21 March 2018 – A 2014 Ipsos Reid Survey commissioned by the Canadian Hospice Palliative Care Association of general practitioners, family physicians and nurses in primary care found that 20-25% of practicing physicians are not very comfortable or not comfortable at all, 50% are only somewhat comfortable and only 25-30% of practicing physicians felt very comfortable providing palliative or end-of-life care (PEoLC).[1] This same survey also found that only 26% of physicians are very comfortable discussing advance care plans (ACP) with patients, and one-quarter of physicians/ nurses across Canada know little or next to nothing about ACP. 67% of physicians indicated that they need more resources and information to have these discussions with their patients. PEoLC education needs to be integrated into all areas of undergraduate and postgraduate curriculum so that it not seen as a separate curricular entity. Patient contact is critical as part of regular mandatory curriculum: "put the student with the dying patient." However, only about 10% of Canadian medical schools offer mandatory undergraduate clinical elective opportunities in palliative care (PC). Demand for mandatory post-grad electives further limits undergraduate elective opportunities in schools with limited clinical capacity. Residency opportunities are in short supply and a lack of ability to fund training for qualified applicants is a reality at all medical schools across the country offering enhanced skills training in PC. **Download/view Society's backgrounder:** https://goo.gl/NfSs4q

Specialist Publications

'Supporting lesbian, gay, bisexual, and transgender inclusivity in long-term care homes: A Canadian perspective' (p.15), in *Canadian Journal on Aging.*

'A minor issue? The shortcomings of the eligibility requirements for medically assisted death in Canada' (p.17), in *Appeal: Review of Current Law & Law Reform.*

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1. 'The Way Forward – Moving Towards an Integrated Palliative Approach to Care,' Canadian Hospice Palliative Care Association, August 2014. **Download/view at:** https://goo.gl/2Yuy7e

U.S.A.

Well illustrated: Visions at the end of life

THE NEW YORK TIMES | Online – 22 March 2018 – As an artist in residence on the palliative care floor of the University of Texas MD Anderson Cancer Center in Houston, I visit with dying patients and their caregivers. These 12 rooms are sacred spaces, and I open the doors carefully to see if art might help. The first moments when I enter a patient's room are fragile and tender. Some patients are very beautiful in repose and seem at peace. Their partners or family members want me to draw them like that. Once a woman whose husband had just died asked their nurse if I would come to their room and draw them lying together. The nurses and doctors were skeptical at first, but they now refer me to patients. I have heard what the nurses tell the patients: "She can draw your memories," they say. "She can draw your dreams." When a patient or caregiver has an image that is deep within themselves and we can make it visible, they often bond with it in a way that makes them feel whole. https://goo.gl/EuS3uP

Specialist Publications

'Staff perspectives of barriers to access and delivery of palliative care for persons with dementia in long-term care' (p.6), in *American Journal of Alzheimer's Disease & Other Dementias.*

'Evaluating palliative care resources available to the public using the Internet and social media' (p.7), in *American Journal of Hospice & Palliative Medicine.*

'Palliative care education in cardiology' (p.10), in *Journal of the American College of Cardiology.*

'Development of valid and reliable measures of patient and family experiences of hospice care for public reporting' (p.13), in *Journal of Palliative Medicine.*

'Extraordinary and compelling: The use of compassionate release laws in the U.S.' (p.16), in *Psychology, Public Policy & Law.*

Noted in Media Watch 8 January 2018 (#545, p.2):

- STATE OF NEW YORK | WNDU-TV (South Bend, Indiana) – 5 January 2018 – **'Researchers studying dreams, visions of dying.'** Dreams and visions of the dying have been well-documented throughout history and across cultures. They often give patients comfort as they approach death, but they have never been studied scientifically – until now.[1] Hospice Buffalo is working on a groundbreaking research study on dreams and visions of the dying. https://goo.gl/TeCVbW

    1. 'End-of-life dreams and visions: A longitudinal study of hospice patients' experiences,' *Journal of Palliative Medicine*, 2014;17(3):296-303. [Noted in the 20 January 2014 issue of Media Watch (#341, p.13)] **Abstract:** https://goo.gl/xh1VWK

Thinking about having a "green" funeral? Here's what to know

THE NEW YORK TIMES | Online – 22 March 2018 – A typical American funeral usually involves a few hallmarks we've come to expect: an expensive coffin, lots of flowers, an embalming for the deceased and a number of other add-ons. But how necessary are those embellishments? Enter the "green burial." The specifics of a green burial vary widely, but typically they require far fewer resources for the care of the body and skip a number of the traditional steps, making them better for the environment. Plus, they can save families on funeral costs. Interest in these pared-down, eco-friendly options has grown as people look for ways to cut their carbon footprint. Nearly 54% of Americans are considering a green burial, and 72% of cemeteries are reporting an increased demand, according to a survey released earlier this year by the National Funeral Directors Association. https://goo.gl/oXS7Jw

Noted in Media Watch 14 April 2014 (#353, p.3):

- NATIONAL PUBLIC RADIO | Online – 10 April 2014 – **'Eco-friendly funerals and death in America today.'** Eco-friendly, personalized funerals. The perfect way to end a low-impact environmentally friendly life. Some are replacing a casket with a burial shroud. Opting to place a family member's cremated remains on the ocean floor. Or going high-tech, putting computer chips in your burial blot. Modernizing the burial ritual reflects the values of an aging baby boomer generation. https://goo.gl/Pzkw4T

House passes bill giving the terminally ill easier access to unproven drugs

THE WALL STREET JOURNAL | Online – 21 March 2018 – The House of Representatives passed a "right to try" bill ... that would make unproven drugs more easily available to terminally ill patients, following changes made to address criticism of a version passed by the Senate. The House voted 276-149 ... in favor of the legislation ... which oversees the Food & Drug Administration (FDA). Proponents say the bill is necessary because desperately ill patients need help getting investigatory drugs. But critics say the measure could undermine clinical research into new prescription drugs. They also point to FDA data that show the regulator already approves more than 99% of such requests. The Senate version of the legislation carried a broad definition of which patients could qualify for such unproven drugs. It would allow access by a patient "diagnosed with a life-threatening disease or condition." Critics of the legislation contend such language could potentially jeopardize much of FDA law by allowing unapproved drugs for non-terminal disease. The House and Senate must reconcile their versions of the legislation before it goes to the president's desk. https://goo.gl/rJEySJ

Noted in Media Watch 19 March 2018 (#555, p.3):

- *THE WASHINGTON POST* | Online – 14 March 2018 – **'House defeats "right-to-try" legislation to allow expanded use of experimental drugs.'** In a major setback for Republicans, the House rejected "right-to-try" legislation that would have allowed seriously ill patients to bypass the Food & Drug Administration (FDA) to get access to experimental treatments. https://goo.gl/unSDBb

N.B. Additional articles on "right-to-try" laws noted in 12 February 2018 issue of Media Watch (#550, p.5).

Seeking LGBT-inclusive hospice care? Here are some things to look for

NEW JERSEY | Out in Jersey (Trenton) – 19 March 2018 – Discrimination against lesbian, gay, bisexual and transgender (LGBT) people is unacceptable in any instance. But it is particularly unforgiveable when encountered in a hospice or palliative care (PC) environment. When an LGBT person has a serious or life-limiting illness and seeks PC or hospice care, they run the risk of isolation and marginalization at the precise time when they most need support. LGBT family members of straight patients seeking hospice care are also vulnerable. A 2016 survey ... found LGBT seniors were frequently mistreated by care center staff.[1] Abuse included cases of verbal and physical harassment, and refusal of basic services. Stripped of any sense of comfort while facing a serious illness some find their situation all the more excruciating. When seeking LGBT-inclusive hospice and PC, it is critically important to know what to look for. https://goo.gl/u3SzAN

Specialist Publications

'Supporting lesbian, gay, bisexual, & transgender inclusivity in long-term care homes: A Canadian perspective' (p.15), in *Canadian Journal on Aging.*

'Experiences and unmet needs of lesbian, gay, and bisexual people with cancer care: A systematic review and meta-synthesis' (p.15), in *Psycho-Oncology*.

1. 'LGBT seniors are being pushed back into the closet,' *The Atlantic*, published online 25 August 2016. https://goo.gl/hFKFSo

Noted in Media Watch 22 January 2018 (#547, p.11):

- *CANADIAN JOURNAL ON AGING* | Online – 16 January 2018 – **'Staying out of the closet: Lesbian, gay, bisexual, and transgender older adults' hopes and fears in considering end-of-life.'** The purpose of this study is to help fill research gaps on lesbian, gay, bisexual, and transgender (LGBT) aging and end-of-life (EoL). The authors sought to better understand the lived experience of older LGBT individuals and examine their concerns associated with EoL. They highlight the idea that identifying as LGBT matters when it comes to aging and EoL care, and underscores the need to consider gender identity and sexual orientation at EoL. **Abstract (inc. list of references):** https://goo.gl/Sbw1q8

Cont.

Noted in Media Watch 1 January 2018 (#544, p.20):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 18 December 2017 – **'End-of-life preparations among lesbian, gay, bisexual, and transgender people: Integrative review of prevalent behaviors.'** Lesbian, gay, bisexual, and transgender (LGBT) people often experience discrimination from health care providers that detrimentally affects their ability to communicate their care preferences. Structural barriers may impede timely and quality care when one is most in need. The aim of this study was to examine the prevalence of end-of-life preparatory behaviors among LGBT people... **Abstract (w. access to references):** https://goo.gl/N9XTzR

  N.B. Additional articles on hospice and palliative care services for LGBT communities noted in this issue of Media Watch.

End-of-life care in Florida

Hospice patients increase as population ages

FLORIDA | *The Florida Times-Union* (Jacksonville) – 18 March 2018 – Florida has the second most hospice patients in the nation. Only California has more, while Texas ranks third, national health care data show. The number of people receiving hospice care in Florida has increased steadily for at least the past 14 years, although there was a slight dip in patients one year about about a decade ago, said Paul Ledford, president and chief executive officer of the Florida Hospice & Palliative Care Association. Florida residents receiving hospice care – either at in-patient facilities or at home – last year are on track to total at least 130,751 admissions state-wide, according to health care data to be published in about two weeks... Total hospice admissions were 128,878 in 2016, and 126,156 in 2015... https://goo.gl/Sf858s

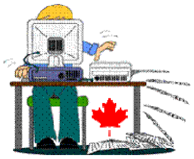
Noted in Media Watch 13 November 2017 (#538, p.4):

- FLORIDA | *Kaiser Health News* – 7 November 2017 – **'Hospice workers who care for the dying don't plan ahead themselves.'** Hospice workers may witness terminal illness and death almost daily, but that doesn't mean they've documented their own end-of-life wishes, a new report finds.[1] A survey of nearly 900 health care workers at a non-profit Florida hospice found that fewer than half had completed advance directives. https://goo.gl/XsSFF1

  1. 'Advance directives in hospice healthcare providers: A clinical challenge,' *American Journal of Medicine,* 2017;130(11):e487-e489 (first published online 7 August 2017). [Noted in the 14 August 2017 issue of Media Watch (#525, p.7)] **Full text:** https://goo.gl/BWoQvQ

Noted in Media Watch 31 July 2017 (#523, p.2):

- FLORIDA | *The News-Press* (Fort Myers) – 28 July 2017 – **'Taking too long to die: Some "terminal" patients can lose hospice benefits.'** For John Tagtmeir hospice care has meant weekly visits from a nurse, equipment to aid his breathing, and powerful painkillers to help ease his eventual passing. That may now be going away. His situation exposes some uncomfortable and largely unknown truths about the limits of Medicare coverage. https://goo.gl/e3jYU6



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

International

Seoul government announces comprehensive measures to prevent lonely deaths

SOUTH KOREA | *The Hankyoreh* (Seoul) – 21 March 2018 – The number of deaths in Seoul involving people without family or friends has risen steadily from 285 in 2013 to 366 in 2017. Sixty-two percent of the victims of "lonely deaths" – dying unexpectedly while living alone – were males aged 45 to 65. In a city where 2.05 million households consist of one or two people – accounting for 54% of all households – lonely deaths are an issue with far-reaching impact. Last year, the city of Seoul conducted a pilot study with neighbourly checkups. Longtime residents, neighborhood association presidents, and resident association members participated in the effort... This year, 26 regions in 17 districts have been selected for support in organizing and providing people to perform the neighbourly checkups. The aim is to have the resident associations serve as a local safety net against lonely deaths. https://goo.gl/d7BrHT

Specialist Publications

'Considerations for introducing legislation on advance decisions in Malaysia' (p.7), in *Asian Bioethics Review.*

'Management of COPD in end-of-life care by Spanish pulmonologists' (p.8), in *COPD: Journal of Chronic Obstructive Pulmonary Disease.*

'Advance care planning in Chinese seniors: Cultural perspectives' (p.11), in *Journal of Palliative Care.*

'The African Palliative Care Association (APCA) Atlas of Palliative Care Development in Africa: A comparative analysis' (p.13), in *The Lancet Global Health.*

'How do people with disabilities die in France today? Current state of end-of-life and dying conditions for adults with intellectual disabilities in France' (p.14), in *Médecine Palliative.*

Why we should let healthcare professionals be conscientious objectors

U.K. | *The Conversation* – 21 March 2018 – For most people, the term "conscientious objection" evokes images of Quakers and pacifists registering to avoid military service. Many countries have a long and honourable tradition of accommodating such conscientious objectors. It might not be about bombs and bullets, but healthcare professionals often find themselves fighting a conscience battle of their own. In the U.K., Canada, Sweden and other countries, conscientious objectors in healthcare have found themselves discriminated against in various ways – whether through dismissal, lack of promotion, or more subtle forms of coercion. Most cases involve doctors, nurses or midwives refusing to perform abortion or euthanasia (or to assist with either). Yet these happen, through historical accident, to be the flashpoint of current controversy. Whatever your personal views on the morality of this or that medical activity or treatment, what is primarily at issue is whether healthcare workers should have their freedom of conscience enshrined in law. You might ask: isn't it already? Well, there are a number of international treaties and conventions, such as the Universal Declaration of Human Rights, to which the U.K. and many other countries are party, and in which freedom of conscience (and freedom of religion, to which it is related, but not identical) is explicitly recognised. https://goo.gl/QpQvHv

Noted in Media Watch 15 January 2018 (#546, p.9):

- *CLINICAL ETHICS* | Online – 8 January 2018 – **'Testing conscientious objection by the norm of medicine.'** This paper proposes that claims of conscientious objection can and should be permitted if they concern kinds of actions which fall outside of the normative standard of medicine, which is the pursuit of health. Medical practice which meets this criterion we call *medicine qua* medicine. If conscientious refusal concerns something consonant with the health-restoring aims of medicine, it entails a desertion of professional duty. If, however, it relates to something other than *medicine qua* medicine, it can rightly be refused. **Abstract:** https://goo.gl/J9Gj8i

Cont.

Noted in Media Watch 19 December 2016 (#492, p.14):

- *CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS*, 2017;26(1):32-43. **'Conscientious objection and "effective referral."'** Physician should not be coerced into involvement of any kind in what they regard as wrong. Such coercion goes against the very principles of liberal democracy. Reasonable accommodation should be given to those whose moral judgment may be at variance with prevailing professional norms. Moral questions should still be given weight within medicine, and disagreements respected. Dedication to the promotion of human welfare should be paramount... **Abstract (inc. list of references):** https://goo.gl/CSzHq7

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

End-of-life care in Scotland

Warning over "unnecessary" hospital admissions for terminally ill patients

U.K. (Scotland) | BBC News (Edinburgh) – 21 March 2018 – The National Health Service (NHS) could be facing an annual bill of more than £470 million to cope with emergency admissions for terminally ill patients, a leading charity has said. Marie Curie said improved community care could avoid unnecessary strain on Scottish hospitals. It found that in 2016 there were nearly 100,000 emergency admissions for people in the last year of their life, costing the NHS £285 million. The charity warned that could almost double over the next twenty years. The Scottish government wants everyone who needs palliative care to have access to it by 2021, with a doubling of services.[1] Marie Curie said there has been a decline over the last five years in the number of emergency beds used by dying people but even if the trend continues to lower more A&E services would still be needed. Richard Meade, head of policy and public affairs Scotland at Marie Curie, said: "While some emergency hospital admissions for people living with a terminal illness are appropriate and necessary, many are not and can often be avoided entirely if appropriate care in the community is provided." https://goo.gl/Xt946g

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

N.B. Marie Curie's 'Data briefing: Emergency admissions' covers England, Scotland and Wales and can be download/viewed at: https://goo.gl/BKDc4o

Specialist Publications

Staff perspectives of barriers to access and delivery of palliative care for persons with dementia in long-term care

AMERICAN JOURNAL OF ALZHEIMER'S DISEASE & OTHER DEMENTIAS | Online – 19 March 2018 – Twenty-two staff participants were interviewed [for this study]. Their experiences were interpreted using phenomenological methodology. Findings yielded three key themes: 1) Confusion; 2) Resource shortages; and, 3) Communication difficulties. Implications for practice include clarification of terminology surrounding palliative care (PC), education of families about dementia and PC, better resource management, and the need to address when PC best fits within the dementia process. **Abstract (inc. list of references):** https://goo.gl/KfFQzE

Journal Watch

'Redefining the 'E' in EBM' (p.17), in *BMJ Evidence-Based Medicine.*

N.B. Additional articles on palliative care for people living with Alzheimer's and other forms of dementia noted in the 19 March 2018 issue of Media Watch (#555, p.13).

Evaluating palliative care resources available to the public using the Internet and social media

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 18 March 2018 – In this cross-sectional study, the most popular Google websites were mostly from national organizations promoting palliative care (PC), whose definitions of PC consistently mention "quality of life" and "relief from symptoms and stress." None of the websites mentioned children, and 77% cited PC as treatment for cancer with less focus on other diseases. No personal stories were included in Google websites, while 60% of YouTube videos included personal stories. Five main themes were generated from 266 YouTube video comments analyzed. The most common was emotionality, of which 91% were positive statements. Facebook and Twitter were mostly used by health-care professionals and not the public. PC resources are mostly positive and consistent with the current definition of PC. Major Internet search engines such as Google and YouTube provide valuable insight into information the public receives about PC. Future development of Internet resources on PC should consider including children and emphasizing PC for all life-limiting illnesses. **Abstract:** https://goo.gl/9HR7NP

Noted in Media Watch 16 October 2017 (#534, p.16):

- *SUPPORTIVE CARE IN CANCER* | Online – 9 October 2017 – **'Palliative care content on cancer center websites.'** The authors conducted a content analysis of 62 [U.S.] National Cancer Institute designated cancer center websites. 10% had no webpage with palliative care (PC) information for patients. Among centers with information for patients, the majority (96%) defined palliative or supportive care, but 30% did not discuss delivery of PC alongside curative treatment, and 14% did not mention provision of care early in the disease process. **Abstract (inc. list of references):** https://goo.gl/6vEYhL

Considerations for introducing legislation on advance decisions in Malaysia

ASIAN BIOETHICS REVIEW | Online – 17 March 2018 – End-of-life care decision-making is not made easier in a multi-cultural and multi-religious society like Malaysia. As such, planning for one's death by making advance decisions can be immensely valuable as it can help healthcare providers in Malaysia to understand better the preferences and wishes of their patients. However, compared to other countries, there is currently no specific legislation on any form of advance decisions in Malaysia despite many doctors voicing a need for them. Unlike the Mental Capacity Act 2005 in the U.K., the Malaysian Mental Health Act 2001 does not cover all instances of incapacity and only applies to those who suffer from a mental disorder as defined in the Act. In the absence of legislation, one could look to ethical guidelines, especially from the Malaysian Medical Council, but find that this can sometimes be problematic. It is argued that a concerted effort involving all relevant parties is required to develop a pragmatic and viable advance decisions framework in Malaysia. **Full text:** https://goo.gl/gLbnzJ

Related

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2018;21(1):1-8. **'The problems and the improvement plan of the hospice/palliative care and dying patient's decisions on Life-Sustaining Treatment Act.'** The act ... took effect on 4 February 2018. However, during the legislation process, some parts of the bill that stakeholders and concerned parties did not see eye to eye were either revised or removed. Moreover, the hospice and palliative care part was added in the last minute before the enactment. As a result, the law includes parts that are not in line with the recommendations from the National Bioethics Committee, thereby causing various problems. **Abstract (inc. list of references):** https://goo.gl/iMgD3g

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.18.

Using motivational interviewing to facilitate death talk in end-of-life care: An ethical analysis

BMC PALLIATIVE CARE | Online – 21 March 2018 – This paper evaluates the ethical permissibility of interventions based on motivational interviewing (MI) in end-of-life (EoL) care whose aim is to facilitate "death talk," that is, disclosure of EoL diagnosis and prognosis to close personal relations, either by the patient directly, or by a health professional with the patient's consent. By increasing the incidence of death talk, it may be possible to reduce the incidence of unprepared bereavement, which may cause psychological morbidity among survivors. We argue that directional, or specific outcome-oriented, MI in this setting may be permissible, all things considered. Unprepared bereavement has considerable health implications for survivors. The bereavement studies literature demonstrates that a lack of preparedness for a loved one's death is a risk factor for secondary psychological morbidity among survivors. The causes of bereavement unpreparedness are not well-known. Even when health professionals provide adequate EoL information to the patient, loved-ones may be unable to prepare for bereavement if the patient abstains from first-personal disclosure of diagnosis/prognosis and withholds consent to professional disclosure of the same. **Full text:** https://goo.gl/Dm4EdZ

Management of COPD in end-of-life care by Spanish pulmonologists

COPD: JOURNAL OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE | Online – 20 March 2018 – Previous studies suggest that patients with this disease receive little palliative care (PC), even in very advanced stages. Around half of the respondents [to an online survey] had no established routines in their departments to offer PC to patients with chronic obstructive pulmonary disease (COPD). There was little communication with end-of-life patients and their families on disease course, mainly associated with a lack of medical training and changes in patient wishes regarding care through the disease course. Communication with end-of-life patients with COPD is poor. **Abstract:** https://goo.gl/uMmsRd

Noted in Media Watch 26 February 2018 (#552, p.13):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 22 February 2018 – **'A new way of organising palliative care for patients with severe chronic obstructive pulmonary disease.'** Although several guidelines recommend those with chronic obstructive pulmonary disease (COPD) should be offered early and integrated palliative care none describe how these recommendations can be operationalised. This article offers insight into the experience of developing and implementing a new palliative outpatient structure for patients with severe COPD. **Abstract (w. access to references):** https://goo.gl/JVPrHx

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

Effectiveness of palliative care interventions offering social support to people with life-limiting illness: A systematic review

EUROPEAN JOURNAL OF CANCER CARE | Online – 24 March 2018 – Responding to the needs of people with life-limiting illness requires consideration of social well-being, including their perception of support from others. Psychosocial palliative care (PC) services and interventions have been developed that facilitate social support, with some evidence for effectiveness. It is possible that psychological and physical benefits operate via mechanisms of social support. However, social support does not appear to have been used appropriately as an outcome of PC interventions. Further research is required to elucidate what forms of social support are most effective to which patients at which time points. It may be illuminating to test different intervention formats and durations or explore individual differences in baseline distress or perceived social support. With increasing financial pressures, it is crucial that economic evaluation takes place alongside testing intervention effectiveness. This systematic review summarises the quantitative evidence of benefits of social support interventions to people with life-limiting illness. Existing evidence suggests that patients presenting with high distress are most likely to benefit from interventions facilitating social support. The authors suggest, based on this review, that clinicians explicitly consider social needs and risk of social isolation as an important domain within holistic care. **Full text:** https://goo.gl/Tkkvzg

The problem of comforting the grieving in the funeral sermon

THE EXPOSITORY TIMES | Online – 15 March 2018 – Despite widespread agreement that the funeral sermon should comfort the grieving, research among the bereaved in the Slovak Republic does not indicate that they perceive the funeral sermon as a factor helpful to them in the period following the funeral. The study comes to a negative answer of whether this was a denominationally-conditioned observation, through a comparison of results from other church environments. After revealing the tension between an identified goal of bringing comfort and its non-achievement (according to the reactions of the bereaved), it is believed that occasion-specific homiletic research is necessary... **Abstract:** https://goo.gl/kHceQg

Ethical challenges for an understanding of suffering: Voluntary stopping of eating and drinking and the wish to hasten death in advanced patients

FRONTIERS IN PHARMACOLOGY | Online – 14 March 2018 – Some persons with advanced disease but no significant cognitive impairments consciously decide to stop taking food and fluids orally, even though they remain physically able to do so. The question is to what extent voluntarily stopping eating and drinking (VSED) may be considered an expression of a wish to hasten death, in the sense that the latter has been defined recently. The authors analyze the data reported in some studies in relation to primary care patients who died as a result of VSED and examine their results in light of the qualitative findings of patients that expressed a wish to die. In their view, VSED can be understood as a response to physical/psychological/spiritual suffering, as an expression of a loss of self, a desire to live but not in this way, a way of ending suffering, and as a kind of control over one's life. Thus, VSED is consistent with the wish to hasten death. Prior to interpreting this act as a deliberate expression of personal autonomy, it is important to explore all possible areas of suffering, including physical symptoms, psychological distress, existential suffering and social aspects. Failure to do so will mean that we run the risk of abandoning a fellow human being to his or her suffering. **Abstract:** https://goo.gl/DgVY6q

Noted in Media Watch 5 March 2018 (#553, p.12):

- *PSYCHO-ONCOLOGY* | Online – 28 February 2018 – **'Assessment of the wish to hasten death in patients with advanced cancer: A comparison of two different approaches.'** The Desire for Death Rating Scale and the short form of the Schedule of Attitudes toward Hastened Death are different approaches to assessing the wish to hasten death (WTHD). Both have clinical threshold scores for identifying individuals with a meaningfully elevated WTHD. The agreement between the two measures, and patient opinions about assessment of the WTHD, are unknown. **Abstract:** https://goo.gl/R6yF4L

N.B. Additional articles on the wish to hasten death noted in the 9 October 2017 issue of Media Watch (#533, p.10).

Noted in Media Watch 29 January 2018 (#548, p.11):

- *JAMA INTERNAL MEDICINE*, 2018;178(1):123-127. **'Voluntarily stopping eating and drinking among patients with serious advanced illness – clinical, ethical, and legal aspects.'** Patients with advanced illnesses sometimes request that physicians help hasten their death. Increasingly in North America and Europe, legal options allow physicians to perform this role. Among death-hastening options, the spotlight has been on physician-assisted death. However, voluntarily stopping eating and drinking (VSED) is also a course that patients may choose. **Abstract:** https://goo.gl/4wN5mX

N.B. Additional articles on VSED noted in this issue of Media Watch.

Palliative Care Network

Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8I

Learning from experiences of feeling heard: A qualitative study of hospice volunteers

ILLNESS, CRISIS & LOSS | Online – 22 March 2018 – What does it feel like when someone really listens to you? Data generated in qualitative interviews with ten individual hospice volunteers illuminate the quality of listening they received (and did not receive) from key role models in their lives. Analysis suggests that occasions of receiving listening are rare and pivotal events that can be used to learn more about how to listen to others, particularly in end-of-life care. The article closes with some recommendations for enhancing emotional support for hospice and palliative care volunteers, and for more training in reflective practice, including new approaches to teaching active empathic listening and communication skills. **Abstract:** https://goo.gl/KvnDpE

> **N.B.** Additional articles on the role of volunteers in hospice and palliative care noted in the 26 February 2018 issue of Media Watch (#552, pp.11-12).

Palliative care education in cardiology

JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY, 2018;71(12):1391-1394. This is the first study to evaluate the quantity and quality of palliative care (PC) education in U.S. cardiology fellowship programs using standards set by current national consensus training and practice guidelines. Results demonstrate that PC skills are important to cardiologists in training and in practice, but cardiology fellowships currently offer incomplete education in essential PC competencies. These findings are consistent with several prior studies that demonstrate deficits in PC training within other subspecialty fellowships. Although this study is limited by small sample size, subjectivity of self-reported data, generalization of findings from academic cardiology programs, and the inherent challenges in assessing education quality, the findings provide a critical starting point for further investigation. This study shows that among crucial PC skill sets, symptom management and advance care planning (ACP) are two of the least well represented in current cardiology training guidelines. To address these deficits, the authors propose the development of a task force to define standardized PC competencies for cardiology trainees and incorporate educational objectives into future guidelines. This will enable cardiologists to better integrate high quality symptom management and ACP techniques into their armamentarium of tools for treating patients with advanced advance heart disease. **Full text:** https://goo.gl/6hpsXz

Related

- *CIRCULATION*, 2018;137(12):1216-1217. **'Paving a better path for patients dying of heart disease.'** The state of medical care at the end of life (EoL) in the U.S. was recently highlighted in the Institute of Medicine's report...[1] However, this report focused mostly on cancer and did not address specific challenges faced by patients with heart disease, which continues to be the most common cause of death in the U.S. This significant omission occurred because most research on EoL care has been conducted on cancer patients, and most care models, including hospice, have been designed to optimize care for that population. **Summary:** https://goo.gl/N4a6j9

    1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in 22 September 2014 issue of Media Watch (#376, p.4)] **Full report:** http://goo.gl/mm4o6W

N.B. 'Palliative care and cardiovascular disease and stroke: A policy statement from the American Heart Association and the American Stroke Association,' *Circulation*, 2016;134(11):e198-e225. [Noted in the 18 September 2017 issue of Media Watch (#530, p.2)] **Abstract:** https://goo.gl/2u9mE2

The voice is as mighty as the pen: Integrating conversations into advance care planning

JOURNAL OF BIOETHICAL INQUIRY | Online – 17 March 2018 – Advance care planning (ACP) allows patients to articulate preferences for their medical treatment, lifestyle, and surrogate decision-makers in order to anticipate and mitigate their potential loss of decision-making capacity. Written advance directives are often emphasized in this regard. While these directives contain important information, there are several barriers to consider: veracity and accuracy of surrogate decision-makers in making choices consistent with the substituted judgement standard, state-to-state variability in regulations, literacy issues, lack of access to legal resources, lack of understanding of medical options, and cultural disparities. Given these issues, it is vital to increase the use of patient and healthcare provider conversations as an ACP tool and to increase integration of such discourse into ACP policy as adjuncts and complements to written advance directives. The authors review current legislation about written advance directives and dissects how documentation of spoken interactions might be integrated and considered. They discuss specific institutional policy changes required to facilitate implementation. The authors explore the ethical issues surrounding the increased usage and recognition of clinician-patient conversations in ACP. **Abstract (inc. list of references):** https://goo.gl/1GCZHX

Related

- *JOURNAL OF PALLIATIVE CARE* | Online – 23 March 2018 – **'Advance care planning in Chinese seniors: Cultural perspectives.'** The adoption of palliative care (PC) in China has been slow, with a curative approach dominating health-care strategies. The authors summarize China's current situation in population aging, PC development, and Chinese cultural values on death and dying, and review the advance directive and end-of-life care preferences among Chinese elderly patients. Current literature recommends the use of indirect communication approaches to determine Chinese seniors' readiness. In individual practice, using depersonalized communication strategies to initiate the discussion is recommended to determine older Chinese seniors' readiness. **Abstract:** https://goo.gl/7Chzef

Noted in Media Watch 19 March 2018 (pp.6-7):

- *ASIAN BIOETHICS REVIEW* | Online – 14 March 2017 – **'An actual advance in advance directives: Moving from patient choices to patient voices in advance care planning.'** At the Center for Healthcare Ethics, Cedars-Sinai Medical Center, Los Angeles, California, significant efforts have focused on embracing the unique and complementary responsibilities of patients (articulating their goals, values, and preferences) and physicians (using medical expertise to reach patient goals) for enabling appropriate plans of care. This includes re-structuring its advance directive form to more accurately represent patient's values as the frame within which physicians are responsible for determining appropriate care. **Full text:** https://goo.gl/75S3LQ

The scope and future direction of child life

JOURNAL OF CHILD & FAMILY STUDIES | Online – 16 March 2018 – Child life specialists work in a variety of healthcare settings and help children and families to cope with stress through play, preparation, and education. The purpose of this study was to examine the current scope of child life practice. Child life specialists, recruited through the listserv of the [U.S.] Association of Child Life Professionals (formerly the Child Life Council), responded to an online survey that examined demographics, work environments and settings, the range of services provided, and perceived levels of competence in providing these services. Respondents indicated that they perform a wide range of activities and feel competent in performing the majority of these activities. However, gaps in academic preparation such as more knowledge about death and dying and increased skills in working with diverse families were identified. **Abstract (inc. list of references):** https://goo.gl/R1abQH

An international legal review of the relationship between brain death and organ transplantation

JOURNAL OF CLINICAL ETHICS, 2018;29(1):31-42. The "dead-donor rule" states that, in any case of vital organ donation, the potential donor should be determined to be dead before transplantation occurs. In many countries around the world, neurological criteria can be used to legally determine death (also referred to as brain death). Nevertheless, there is considerable controversy in the bioethics literature over whether brain death is the equivalent of biological death. This international legal review demonstrates that there is considerable variability in how different jurisdictions have evolved to justify the legal status of brain death and its relationship to the dead-donor rule. The authors review approaches that are representative of many different jurisdictions – the U.S. takes an approach similar to that of many European countries; the U.K.'s approach is followed by Canada, India, and influences many other Commonwealth countries; Islamic jurisprudence is applicable to several different national laws; the Israeli approach is similar to many Western countries, but incorporates noteworthy modifications; and, Japan's relatively idiosyncratic approach has received some attention in the literature. Illuminating these different justifications may help develop respectful policies regarding organ donation within countries with diverse populations and allow for more informed debate about brain death and the dead-donor rule. **Abstract:** https://goo.gl/sKvahu

N.B. Additional articles on defining "brain dead" noted in the 26 February 2018 and 20 November 2017 issues of Media Watch (#552, p.2 and #539, p.1, respectively).

End-of-life care in Italy

The "ARIANNA" Project: An observational study on a model of early identification of patients with palliative care needs through the integration between primary care and Italian home palliative care units

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 March 2018 – In Italy, palliative care (PC) is often provided only in the last phase of life and for oncological patients, with a fragmented service. In this multicenter prospective observational study, nine hundred thirty-seven patients, out of a total pool of 139,071, were identified by GPs as having a low life expectancy and PC needs. Of these, 556 (59.3%) were non-oncological patients. The GPs sent 433 patients to the home palliative care units for multidimensional assessment, and 328 (75.8%) were placed in the care of both settings (basic or specialist). For all patients included in the study, both oncological and non-oncological patients, there was a high rate of death at home, around 70%. This study highlights how a model based on early identification, multidimensional evaluation, and integration of services can promote adequate PC, also for non-cancer patients, with a population-based approach**. Abstract:** https://goo.gl/Le2Pr9

Noted in Media Watch 3 October 2016 (#482, p.11):

- *EUROPEAN JOURNAL OF PUBLIC HEALTH* | Online – 28 September 2016 – **'Hospital, local palliative care network and public health: How do they involve terminally ill patients?'** Over one quarter of health care expenditure is spent on patients in the last year of life. The authors findings support a progressive shift of the economic burden of end-of-life care from the hospital sector to the long-term care sector, with consequent implications for supply, organization and funding of these sectors. **Full text:** https://goo.gl/bFG5wo

Noted in Media Watch 1 June 2015, #412 (p.12):

- *RECENTI PRORESSI IN MEDICINA*, 2015;106(5):201-202. **'Early palliative care.'** Several randomized controlled trials have demonstrated the efficacy of early palliative care (PC), in particular in cancer patients and, more recently, also in patients with other advanced life-threatening illnesses. Results have been consistent in showing that early PC improves quality of life without negatively affecting survival compared with more aggressive treatment options. **Full text:** https://goo.gl/OrCyCi

  N.B. Italian language article.

Economic impact of early inpatient palliative care intervention in a community hospital setting

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 March 2018 – Inpatient palliative care (PC) programs have demonstrated financial benefit for the hospital and improved quality of care for patients with advanced disease. Previous studies on this subject have focused on comparisons between palliative and traditional care. The financial and clinical effects of early versus late PC intervention are less well documented. The aims of this study were to review the financial and quality outcomes that early PC intervention has on appropriate inpatients in the community hospital setting. Patients in the early intervention group realized a reduction in length of stay (LOS) and a significant cost reduction. In the analysis of the entire group, the average LOS with early intervention was 6.09 days versus 16.5 days with late intervention. The early intervention group demonstrated an earlier transition to comfort care, earlier referral to outpatient hospice, and did not have a negative effect on mortality. **Abstract:** https://goo.gl/UJhHqT

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

Development of valid and reliable measures of patient and family experiences of hospice care for public reporting

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 March 2018 – Increasingly, [in the U.S.] dying patients and their families have a choice of hospice providers. Care quality varies considerably across providers; informing consumers of these differences may help to improve their selection of hospices. The object of this study was to develop and evaluate standardized survey measures of hospice care experiences for the purpose of comparing and publicly reporting hospice performance. Results also highlight important opportunities to improve the quality of hospice care, particularly with regard to addressing symptoms of anxiety and sadness, discussing side effects of pain medicine, and keeping family informed of the patient's condition. **Abstract:** https://goo.gl/5Pa6iQ

Noted in Media Watch 21 August 2017 (#526, p.2):

- U.S. | *Kaiser Health News* – 18 August 2017 – **'Medicare unveils "skeletal" site for hospice comparison shopping.'** The Centers for Medicare & Medicaid Services released Hospice Compare, a consumer-focused website that lets families compare up to three hospice agencies at a time, among 3,876 nationwide. But the measurements of quality, which are self-reported by hospices, have limited utility, some experts say. Over three-quarters of hospices scored at least 91% out of 100 on six of the seven categories, a recent paper found.[1] https://goo.gl/HbENXG

    1. 'Challenges of measuring quality of community-based programs for seriously ill individuals and their families,' *Health Affairs*, 2017;36(7):1227-1233. [Noted in the 10 July 2017 issue of Media Watch (#520, p.10)] **Abstract (inc. list of references):** https://goo.gl/qQxoBD

The African Palliative Care Association (APCA) Atlas of Palliative Care Development in Africa: A comparative analysis

THE LANCET GLOBAL HEALTH, 2018: 6(Suppl.2):S21. The authors aimed to develop and deploy a set of indicators to measure the current state of palliative care (PC) development in Africa according to WHO's Public Health Strategy for integrating PC, including policies, availability and access to medicines, education, and service provision. Surveys were received from 48 countries. Uganda, South Africa, and Kenya have the highest number of specialised hospice and PC services (71% of identified services); 19% (9/48) have no identified hospice and PC services. 22% (12/48) indicated having stand-alone PC policies, and 42% (20/48) reported having a dedicated person for PC in the Ministry. Zambia, Uganda, South Africa, Kenya, Ghana, and Egypt reported some official form of physician accreditation. Opioid consumption per capita was low (75% of countries had <1 mg consumption per head per year) compared to the global average (62 mg), with the highest consumption in Mauritius, South Africa, Namibia, and Morocco. 54% (26/48) reported having a national PC association. There is limited PC development in Africa, but there is also a significant improvement in the number of countries with hospice and PC services, compared to previous reports. Improvements in advocacy were identified, with more than half of countries reporting a national PC association. **Abstract:** https://goo.gl/RPwVHc

Cont.

Related

- *INTERNATIONAL JOURNAL OF CLINICAL MEDICINE*, 2018;9(3). **'Palliative care, suffering, death trajectory: A view of end-of-life care related issues in sub-Saharan Africa.'** Despite the demands of competing healthcare systems in sub-Saharan Africa (SSA) counties, because of the "needs versus resource" tensions, health care policy makers/managers in SSA countries need to work on the issue of a dignified, death trajectory at end of life (EOL) that is as free of pain and suffering as possible for its citizenry, whilst continuing to battle the ravages of preventable and chronic illnesses known to contribute to high mortality and morbidity. In so doing they should be careful not to be caught up in setting up EOL or palliative care (PC) services that will assume a "business role," as opposed to a value-based PC system. **Full text:** https://goo.gl/CCmN3j

- *SCANDANAVIAN JOURNAL OF CARING SCIENCES* | Online – 24 March 2018 – **'Assessment of palliative care needs of patients/families living with cancer in a developing country.'** This article focused on needs as expressed by patients and families and offers a useful guide to develop a model for integration of palliative care (PC) activities. The findings of this study reveal that patients who are undergoing follow-up care and cancer treatment or investigation are clearly concerned about receiving information on a range of cancer issues. The authors conclude that patients are able to deal with the disease more effectively when hospitals set up a PC team or unit to carry out proper assessment of patients living with cancer. **Abstract:** https://goo.gl/cE8BHN

N.B. Additional articles on the development of palliative care in Africa noted in the 5 February 2018 and 5 September 2016 issues of Media Watch (#549, pp.5,12 and #478, p.9, respectively).

Developing a service improvement initiative for people with learning disabilities in hospice settings

NURSING STANDARD, 2018;32(30):49-54. People with learning disabilities are often marginalised in healthcare, including in hospice settings, and as a result may not receive effective end-of-life care (EoLC). Research in hospice settings has identified that many staff lack confidence, skills and knowledge in caring for people with learning disabilities, which can have a negative effect on the care these individuals receive. To address these issues, the author proposes a service improvement initiative, which she developed as part of her learning disability nursing degree programme. This proposed initiative aimed to enhance EoLC for people with learning disabilities through the implementation of a community learning disability link nurse in the hospice setting. **Abstract:** https://goo.gl/M1seHx

Related

- *MÉDECINE PALLIATIVE* | Online – 19 March 2018 – **'How do people with disabilities die in France today? Current state of end-of-life and dying conditions for adults with intellectual disabilities in France.'** This article presents the results of a thorough survey carried out in a French region on the last part of the existence of adults with disabilities supported by institutions. This raises many questions for those with intellectual disabilities, such as the quality of their end-of-life experience and the still weak cooperation between their carers and palliative care teams. **Abstract:** https://goo.gl/d1QPMm

N.B. Additional articles on end-of-life care for people living with intellectual disabilities noted in the 1 January and 5 March 2018 issues of Media Watch (#544, pp.21-22 and #553, p.5, respectively).

Deaths after feeding-tube withdrawal from patients in vegetative and minimally conscious states: A qualitative study of family experience

PALLIATIVE MEDICINE | Online – 23 March 2018 – Families of patients in vegetative or minimally conscious states are often horrified by the suggestion of withdrawing a feeding tube, even when they believe that their relative would not have wanted to be maintained in their current condition. Very little is known about what it is like to witness such a death. Interviewees were usually anxious in advance about the nature of the death and had sometimes confronted resistance from, and been provided with misinformation

Cont.

by, healthcare staff in long-term care settings. However, they overwhelmingly described deaths as peaceful and sometimes even as a "good death." There was (for some) a significant "burden of witness" associated with the length of time it took the person to die and/or distressing changes in their appearance. Most continued to voice ethical objections to the manner of death while considering it "the least worst" option in the circumstances. Staff need to be aware of the distinctive issues around care for this patient group and their families. It is important to challenge misinformation and initiate honest discussions about feeding-tube withdrawal and end-of-life care for these patients. Families (and staff) need better support in managing the "burden of witness" associated with these deaths. **Abstracts:** https://goo.gl/sxQHAa

"Palliative sedation"? A retrospective cohort study on the use and labelling of continuously administered sedatives on a palliative care unit

PALLIATIVE MEDICINE | Online – 20 March 2018 – Sedatives are frequently used towards the end of life. However, there is scarce information when their use is labelled as "palliative sedation." In this study, of the 192 patients, 149 (78%) patients received continuous sedatives within the last week of life. The prevalence of delirium/agitation was significantly higher in patients with continuous sedatives compared to those without continuous sedatives at admission to the unit and on the day before death. The term "(palliative) sedation" was used in the records for 22 of 149 (15%) patients with continuous sedatives. The prevalence of delirium/agitation was associated with the administration of continuous sedatives. There was no consistent pattern regarding labelling the use of continuous sedatives as "(palliative) sedation." Multicentre mixed-methods research is needed for a better characterization of sedation practices in palliative care. **Abstract:** https://goo.gl/EU4zEA

Related

- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 20 March 2018 – '**Continuous deep sedation until death" A Swiss death certificate study.**' In 2013, physicians sedated four times more patients continuously until death (6.7% in 2001; 24.5.5% in 2013). Four out of five sedated patients died in hospitals, outside specialized palliative care units, or in nursing homes. Forgoing life-prolonging treatment with the explicit intention to hasten or not to postpone death combined with intensified alleviation of symptoms was very strongly associated with continuous deep sedation. **Abstract (inc. list of references):** https://goo.gl/U4msm3

N.B. Additional articles on palliative sedation noted in the 19 March 2018 issue of Media Watch (#555, p.12).

Experiences and unmet needs of lesbian, gay, and bisexual people with cancer care: A systematic review and meta-synthesis

PSYCHO-ONCOLOGY | Online – 15 March 2018 – Fifteen studies that included lesbian, gay, and bisexual (LGB) people living with or beyond cancer were included in the review. Studies including gender minorities were not identified. Most of the study participants were sexual minority women with breast cancer or sexual minority men with prostate cancer. Meta-synthesis of 106 individual findings generated six overarching themes pertaining to sexual orientation disclosure, experiences and fear of homophobia, positive and negative health-care professional behaviors, heterocentric systems and care, inadequacy of available support groups, and unmet needs for patient-centered care and LGB-specific information. Lesbian, gay, and bisexual people often reported feelings of anxiety, invisibility, isolation, and frustration throughout the cancer care continuum. **Abstract:** https://goo.gl/Lu8mrg

Related

- *CANADIAN JOURNAL ON AGING* | Online – 19 March 2018 – '**Supporting lesbian, gay, bisexual, and transgender inclusivity in long-term care homes: A Canadian perspective.**' The authors found lesbian, bay, bisexual and transgender (LGBT) inclusivity training was the most commonly adopted strategy among the long-term care homes surveyed. Study findings suggested practices more visible to residents and families, such as LGBT-themed programming, inclusive language and symbols, or joint initiatives with LGBT communities, were less commonly adopted because of anticipated negative resident/family reactions. **Abstract (inc. list of references):** https://goo.gl/J4DFyH

Extraordinary and compelling: The use of compassionate release laws in the U.S.

PSYCHOLOGY, PUBLIC POLICY & LAW | Online – accessed 24 March 2018 – In 1984, federal compassionate release laws were established, allowing for the release of inmates given "extraordinary and compelling circumstances" not present at sentencing. Many states established similar laws. Despite possible financial and ethical benefits of compassionate release, few inmates have been released under these laws. This research explores why. In Study 1, to assess the scope of this legislation, the authors provided a compendium of relevant laws, including information on jurisdictions with such laws, criteria for release outlined in each law, and exceptions that may preclude release. Results demonstrated that as of 2016, 46 jurisdictions had a compassionate release law in place. The most frequently cited criterion for release was having a chronic illness. In Study 2, to assess the possibility that public sentiment presents obstacles to using these statutes, the authors probed members of the public and prison wardens on perceptions of the laws, including factors (i.e., criminal history and offense type) associated with willingness to recommend release of a chronically ill inmate. Both community members and wardens were generally supportive of compassionate release, especially for non-violent inmates and those with no criminal history. To explain why these statutes are underutilized, they comment on the complexity and diversity of mechanisms involved in correctional bureaucracies and propose a cost-benefit framework in which the risk of reoffending and loss of retributive opportunity outweigh pragmatic benefits of release on compassionate grounds. **Abstract:** https://goo.gl/Vjo1zc

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

Valuing health at the end of life: A review of stated reference studies in the social sciences literature

SOCIAL SCIENCE & MEDICINE, 2018;204(5):39-50. This paper reviews the empirical evidence in the published social sciences literature relevant to the following research question: "Do members of the public wish to place greater weight on a unit of health gain for end-of-life (EoL) patients than on that for other types of patients?" Twenty-three studies met the authors' inclusion criteria and were included in the review. Choice exercises were the most common method used to elicit preferences; other approaches included budget allocation, person trade-off and willingness-to-pay. Some studies found that observed preferences regarding EoL patients are influenced by information about the patients' ages. Overall, the evidence is mixed, with eight studies that report evidence consistent with a "premium" for EoL treatments and 11 studies that do not. **Abstract:** https://goo.gl/QFL9E9

End-of-life care in Austria

End-of-life therapy for patients dying with cancer: A retrospective database study

WIENER MEDIZINISCHE WOCHENSCHRIFT | Online – 13 March 2018 – The topic of "medical oversupply at the end-of-life (EoL)" is being discussed intensively internationally. The aim of this paper is to present the data of EoL care in one region in Austria (Lower Austria). The data basis for the EoL indicators was the routine data ... of the Lower Austrian District Health Insurance Fund (NÖGKK) from 2015. 2,788 cancer patients ... were included. 61.1% died in a hospital, 17.9% of them on the day of admission. In 16.2% of all patients, death occurred on a palliative care unit, 9.3% died in an intensive care unit. The hospitalization rate 30 days before death was 61.6%. Hospital admission was more common in men than in women. 9.4% of total deaths received chemotherapy, radiotherapy, or monoclonal antibodies within the last 30 days. In international comparison, the region of Lower Austria shows very high hospital admission and hospital mortality rates. Further investigations for the entire country ... are therefore desirable. The establishment of a discussion about the medical oversupply at the EoL in Austria, including appropriate care concepts and care models, is needed. **Abstract (inc. list of references):** https://goo.gl/zzkhv7

> **N.B.** German language article.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *APPEAL: REVIEW OF CURRENT LAW & LAW REFORM*, 2018;23:41-64. **'A minor issue? The shortcomings of the eligibility requirements for medically assisted death in Canada.'** In Canada, it is illegal to assist a person under 18 years of age in ending their own life meaning minors are prohibited from receiving medical assistance in dying (MAiD). This prohibition is based on already accepted (and applied) arguments related to the protection of children, "who are particularly vulnerable both by virtue of their age and their disability, disease or illness"; and, arguments that children cannot make MAiD decisions because of their inexperience and immaturity. However, while minors are prohibited from making MAiD decisions, this does not mean they are also immune from the disabilities and diseases that lead to intense, intolerable pain, or that they are against obtaining MAiD. The Canadian Paediatric Surveillance Program recently reported minors are already approaching doctors about MAiD.[1] Though these conversations with minors about assistance in dying are still "relatively rare," the possibility of such scenarios (and the prospect of paediatric illness) requires a reconsideration of those accepted arguments; they also require a review of arguments regarding bodily autonomy and mature minors. **Full text:** https://goo.gl/2FsNTx

    1. '2016 Survey,' Canadian Paediatric Surveillance Program, October 2017. Click on 'CPSP 2016' and scroll down to 'Medical assistance in dying: Infants, children, and adolescents' (pp. 34-35). [Noted in the 30 October 2017 issue of Media Watch (#536, p.3)] **Download/view report at:** https://goo.gl/FeiSgs

Journal Watch

Editorial

Redefining the 'E' in EBM

BMJ EVIDENCE-BASED MEDICINE, 2018;23(2):46-47. The philosopher of science, Thomas Kuhn, would probably have called our reliance on biomedical journal trial evidence a paradigm. It has served us well, allowing the building of the philosophical and practical backbone of evidence-based healthcare. However, like all paradigms sooner or later it has begun to creak. Our reliance on journal articles needs a redefinition, if not a shift. In the last decade, evidence has accumulated, across a spectrum of different interventions, that journal publications cannot be trusted. Article reports of clinical trials suffer from a grave illness which is curable, but needs a concerted approach to prevent the growing threat of reporting bias. When some of us started looking at the alternative sources of evidence for our Cochrane review of neuraminidase inhibitors for influenza nearly a decade ago, we discovered that below every 10-page trial report lies a far deeper and more complex web of data and information needing attention. That is, if the trial was published in the first place. The first problem is sheer bulk. For every page of journal article, there may be up to 8,000 pages of regulatory data on the same clinical trial. We call it a compression factor. The next problem is bias. **Full text:** https://goo.gl/H5pYee

Media Watch: Editorial Practice

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

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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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