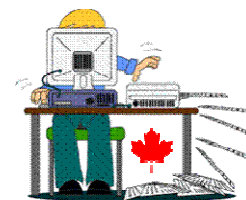


Media Watch...

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

“Stigmatisation of the term [palliative care] among patients, professionals, and the public continues to counter positive messages about its benefits,” ‘Changing perceptions is more important than changing names’ (p.8), in *British Medical Journal*.

Canada

Ageing and Dying in Prison: An Investigation into the Experiences of Older Individuals in Federal Custody

CORRECTIONAL INVESTIGATOR OF CANADA (CIC) & CANADIAN HUMAN RIGHTS COMMISSION (CHRC) | Online – 28 February 2019 – Some older, long-serving federally sentenced offenders are being warehoused behind bars well past their parole eligibility dates. There is no legal or policy recognition that older individuals represent a vulnerable population in prison or that they have unique characteristics, needs and rights which must be respected and met. As a result, their health, safety, dignity and human rights are not adequately protected. Federal penitentiaries were never intended or physically designed to accommodate an aging inmate population. The physical infrastructure of institutions does not adequately meet the needs of older individuals in federal custody. Correctional healthcare costs are rising as the number of aging individuals in federal custody with chronic disease increases. Offenders with terminal illness and those requiring palliative care are living out their single greatest and expressed fear – dying in prison. Prison is no place for a person who requires end-of-life care (EoLC). Federal corrections lacks adequate, compassionate and

responsive release options for older individuals in federal custody who do not pose an undue risk to public safety. Community alternatives are lacking and are not well resourced. There is a clear need for an integrated, comprehensive and funded National Older Offender Strategy that meets the characteristics and needs of older individuals in federal custody, and that ensures the protection of their human rights. **Download/view at:** <http://bit.ly/2GP4aZr>

Extract from CIC & CHRC report

Sick, palliative and terminally ill individuals continue to live out their single greatest and expressed fear – dying in prison. Prison is an unsuitable place for an individual who requires EoLC. Correctional Service of Canada should not be in the business of providing palliative or EoLC, nor should it facilitate or enable medically assisted death to take place in federal correctional facilities. Coordinated and accelerated case management of seriously or terminally ill individuals is required between correctional and parole authorities.

N.B. Additional articles on Canada’s aging prison population noted in 25 June 2018 issue of Media Watch (#569, p.2). A compilation of selected articles, reports, etc., on EoLC in the prison system noted in past issues of Media Watch is posted on the Palliative Care Network website. **Download/view at:** <http://bit.ly/2RdegnL>

New Ontario Health super agency and coordinated health teams announced

ONTARIO | CTV News (Toronto) – 26 February 2019 – Ontario is merging 20 health agencies into one super agency and will establish local health teams to co-ordinate care as part of a system overhaul. Health Minister Christine Elliott ... says too much time is spent maintaining a fragmented system and far too many people believe it is the patient or family's job to navigate the complicated landscape. A new agency, called Ontario Health, will consolidate local health integration networks, Cancer Care Ontario, eHealth Ontario and several other agencies. As well, Ontario Health Teams will be established to provide what Elliott calls seamless access to health services, including primary care, hospitals, home and community care, palliative care, residential long-term care, and mental health and addictions services. The government says people will still be able to choose who

provides their care, and more choices will be available through technology, such as giving patients an option to securely access their electronic health records and virtual care options. <http://bit.ly/2EbGFGe>

Health Quality Ontario **Qualité des services de santé Ontario**

'Palliative Care at the End of Life'

Download/view at: <http://bit.ly/2tCCKHe>

N.B. Noted in 4 July 2016 issue of Media Watch (#469, p.2). Additional articles on the provision and delivery of palliative care in the province also noted in this issue of the weekly report.

N.B. See 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, September 2018. [Noted in 24 September 2018 issue of Media Watch (#582, p.1)] **Download/view (scroll down to foot of page and 'Related Links')** at: <http://bit.ly/2EBoNGm>

Noted in Media Watch 28 January 2019 (#599, p.8):

- *CANADIAN JOURNAL ON AGING* | Online – 24 January 2019 – '**An analysis of documents guiding palliative care in five Canadian provinces.**' A systematic search was conducted examining documents at the national level and across five provinces (Alberta, Ontario, Saskatchewan, Manitoba, and Quebec). Twenty-five documents were selected based on inclusion criteria from 273 documents identified in the systematic search. The majority of these documents were created nationally (48%) or in Ontario (28%). Documents varied in palliative topics discussed... A minimal number of palliative care guiding documents were found. All documents lacked consistency on palliative topics. **Abstract (w. list of references):** <http://bit.ly/2H5VM73>

U.S.A.

Citizens Medical Center adopts new do-not-resuscitate policy

TEXAS | *Victoria Advocate* – 27 February 2019 – The board of Citizens Medical Center approved a new do-not-resuscitate (DNR) policy to comply with state law. The hospital's new policy states that a patient's wish to bypass resuscitation if they stop breathing or if their heart stops beating must meet certain requirements before a DNR order is valid. All patients at Citizens will receive CPR or advanced cardiac life support if they're in the midst of cardiac or respiratory arrest, unless they have a valid DNR order specifying otherwise. The policy was adopted in accordance with Senate Bill 11, which went into effect last year. The legislation is the first time that DNR orders have been regulated statewide in hospitals and other healthcare facilities. The major difference under the new law is that physicians in a Texas hospital cannot unilaterally impose a DNR order in most cases. Although most Texas hospitals already required physicians to get consent before approving a DNR order, the law creates a uniform policy throughout the state. Previously, a patient at Citizens or their next-of-kin could notify the physician if they wanted a DNR order in certain circumstances, explained Dr. Daniel Cano, the hospital's chief medical officer... The physician would write the order and the process would stop there, Cano said. <http://bit.ly/2NyFvZM>

Why crying over a terminal patient made me a better doctor

THE WASHINGTON POST | Online – 24 February 2019 – It is believed that depersonalization prevents contamination of the patient-doctor relationship by emotions and ensures a commitment to objectivity. This also preserves the long-standing archetype of the infallible, unflappable and sagacious physician. Given this context, crying is viewed as an extreme emotional behavior that evinces instability and an unsuitability to grapple with thorny matters such as disease and death. As physician Paul Rousseau noted in a 2003 article ... “Crying was equated with inadequacy, personal and emotional weakness, incompetence, and unprofessional behavior.”¹ And though there is an understanding that it may inevitably happen, crying is expected to take place alone in the isolated margins of parking lots, call rooms and stairwells. Despite the condemnations, studies show that there are plenty of tears in medicine.² A 2009 study noted that 69% of students and 74% of interns self-reported crying for reasons pertaining to medicine. Specialists such as pediatric oncologists reported crying as part of their range of reactions to patient death.³ Surveys of Australian and Dutch physicians further reflect the universality of crying in medicine.^{4,5} <https://wapo.st/2XeW8xU>

1. ‘Physician crying,’ *American Journal of Hospice & Palliative Medicine*, 2003;20(4):251-252. **Download/view at:** <http://bit.ly/2TkpSdT>
2. ‘Crying: Experiences and attitudes of third-year medical students and interns,’ *Teaching & Learning in Medicine*, 2009;21(3):180-187. **Abstract (inc. link to references):** <http://bit.ly/2H0Tuq4>
3. ‘Grief reactions and impact of patient death on pediatric oncologists,’ *Pediatric Blood & Cancer*, 2015;62(1):134-142. [Noted in 22 September 2014 issue of Media Watch (#376, p.15)] **Abstract:** <http://bit.ly/2ThJ2AM>
4. ‘Crying in hospitals: A survey of doctors,’ nurses’ and medical students’ experience and attitudes,’ *Medical Journal of Australia*, 1997;166(1):13-16. **Abstract (via PubMed):** <http://bit.ly/2Vit1b5>
5. ‘Half of Dutch doctors cried at work last year, survey finds,’ *British Medical Journal*, published online 11 December 2015. **Introductory paragraph:** <http://bit.ly/2VaMgDE>

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://bit.ly/2RPJy9b>



Doctors do cry

INDIAN JOURNAL OF MEDICAL ETHICS, 2014; 11(4):249-251. Even though humanity is the cornerstone of medicine, depersonalisation has somehow crept into the physician-patient relationship and crying is considered incompatible with the image of a good physician, who is supposed to be strong, confident and fully in charge. Thus, crying has been equated to weakness and, at times, incompetence. This could be attributed to the fact that our medical curriculum has ingrained in us the belief that emotion clouds rationality and prevents us from being objective while making decisions regarding a patient’s clinical progress. Our curriculum fails to teach us how to handle emotional situations, witness the dying process, communicate bad news, interact with the bereaved during the period of grief ... following death, and reduce professional stress involved in working with newly bereaved persons. **Abstract:** <http://bit.ly/2tBqTje>

N.B. Noted in 17 November 2014 issue of Media Watch (#384, p.7).

Specialist Publications

‘Should doctors cry at work?’ (p.9), in *British Medical Journal*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MARYLAND | *The Baltimore Sun* – 1 March 2019 – ‘**Medically assisted suicide bill moves forward in Maryland General Assembly.**’ After failing three times in recent years, a bill that would allow terminally ill Maryland residents to obtain prescription drugs to end their own lives is moving forward in the state’s General Assembly. Two House of Delegates committees jointly voted to advance the ‘End of Life Options Act’ to the full chamber, which will debate the measure next week. <http://bit.ly/2T9iPW7>
- COLORADO | *The Summit Daily* (Frisco) – 1 March 2019 – ‘**125 Coloradans sought aid-in-dying medication in 2018, a 74% increase from 2017.**’ Colorado got its first look at how the controversial End-of-Life Options Act played out in 2017, offering terminally ill individuals in the state the choice to request aid-in-dying medications for the first time. As the program enters its third year, Coloradans are using the option more often. <http://bit.ly/2GW7NwL>
- OREGON | Oregon Health Authority – 25 February 2019 – ‘**Oregon Death with Dignity Act 2018: Data Summary.**’ In 2018, 249 people received prescriptions. As of 22 January 2019, 168 people had died in 2018 from ingesting the prescribed medications, including 11 who had received the prescriptions in previous years. Characteristics of patients were similar to those in previous years: most patients were aged 65 years or older and most had cancer. **Download/view at:** <http://bit.ly/2Trw4R8>

International

Let’s stop the war talk when it comes to cancer

IRELAND | *The Irish Times* (Dublin) – 25 February 2019 – While it can be traced back centuries, the modern use of military terminology in medicine received a boost when, in 1971, the then U.S. president Richard Nixon publicly declared “war” on cancer and referred to it as a “relentless and insidious enemy.” It has evolved pretty much unchecked since then. We speak to patients about “killer cells” and “magic bullets” We refer to “beating illness” and remind people to “keep up the good fight.” Whatever else, don’t give in. It’s a blunt message: cancer will “beat you” because you lack courage. This is absolutely unfair to most patients. The meek, the mild or those who are depressed may be neither inclined nor able to respond to exhortations to fight back. And unable to respond, some people will feel they have “failed” themselves, their families and their medical team. <http://bit.ly/2Vjw17i>

N.B. Additional articles on the use of metaphors in relation to “combating” life-limiting or life-threatening illness, notably in cancer, noted in 4 February 2019 issue of *Media Watch* (#600, p.5).

Dying at home: [New Zealand’s] aging population stoking growth in home care services

NEW ZEALAND | *Stuff.com* (Wellington) – 24 February 2019 – Demand for in-home end-of-life care is increasing as baby boomers reach their 70s and 80s and elect to be looked after at home rather than move into a care facility. New Zealand’s growing aging population is putting pressure on the health services for the elderly. Stats New Zealand predicts that the number of people over 65 will make up almost a quarter of the population by the late 2030s. Tracking alongside is the death rate, which is expected to rise 50% to 45,000 by 2038, levels not seen since the 1940s and 1950s. All this has the po-

tential to be a perfect storm where demographics meet a cluster of pressures facing the aged care sector. <http://bit.ly/2SYSBp6>

Specialist Publications

‘Preparedness for caregiving: A phenomenological study of the experiences of rural Australian family palliative carers’ (p.11), in *Health & Social Care in the Community*.

Cont.

Noted In Media Watch 23 April 2018 (#560, p.15):

- *PALLIATIVE MEDICINE* | Online – 18 April 2018 – ‘**How family caregivers help older relatives navigate statutory services at the end of life: A descriptive qualitative study.**’ A key challenge in meeting the palliative care needs of people in advanced age is the multiple healthcare and social service agencies typically involved in their care. The “patient navigator” model, originally developed in cancer care, is the professional solution most often recommended to address this challenge. However, little attention has been paid, or is known, about the role that family carers play in enabling their dying relatives to negotiate service gaps. In this study, fragmentation of services was the key concern, causing distress both for the older person and their family caregivers. **Abstract:** <http://bit.ly/2U3lfC0>

Specialist Publications

Cancer communication outside of the physician-patient relationship: The experience of communicating and understanding the meaning of prognosis

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 28 February 2019 – Studies of patient-physician communication of prognosis in oncology highlight areas where misunderstanding occurs: understanding consequences of treatment, likelihood of treatment success, probability of cure, status/progression of illness, and prognosis. Theories proposing mechanisms that underlie this discrepancy cannot account for all instances of misunderstanding, including when complete and direct physician disclosure occurs. Prior research focused on patient-physician communication event(s) and immediate antecedents and consequences. However, less is known about what happens to information once it has been communicated and how a patient’s process to interpret the meaning of their experience affects their understanding of it. This study explores this question by examining patient communication with sources of information other than treating physicians. Participants consulted a variety of additional sources to give context and understanding to their communicated prognosis. These were important contributors to how they understood their prognosis and incorporated that understanding. They in-

cluded family, friends/acquaintances, cancer survivors, support/survivor groups, secondary healthcare staff, and relevant informational materials. Different motivations for seeking out these sources were also expressed. Participants expressed a link between their understanding of their prognosis and the variety of outside sources they enlisted for input and support. **Abstract:** <http://bit.ly/2SAa3Lq>

Publishing Matters

‘**Big pharma is embracing open-access publishing like never before**’ (p.17), in *Nature*.

‘**Avoiding predatory journals: Quick peer review processes too good to be true**’ (p.17), in *Nursing Forum*.

‘**Guidelines for open peer review implementation**’ (p.17), in *Research Integrity & Peer Review*.

‘**A walk on the wild side: “Predatory” journals and information asymmetries in scientific evaluations**’ (p.18), in *Research Policy*.

Assessing relationships between Muslim physicians’ religiosity and end-of-life healthcare attitudes and treatment recommendations: An exploratory national survey [in the U.S.]

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 27 February 2019 – Research demonstrates that the attitudes of religious physicians toward end-of-life (EoL) care treatment can differ substantially from their nonreligious colleagues. While there are various religious perspectives regarding treatment near the EoL, the attitudes of Muslim physicians in this area are largely unknown. This article attempts to fill in this gap by presenting American Muslim physician attitudes toward EoL care decision-making and by examining associations between physician religiosity and these attitudes. Most physicians [i.e., survey respondents] reported that religion was either very or the most important part of their life

Cont.

(89%). Physicians who reported consulting Islamic bioethics literature more often had higher odds of recommending active treatment over hospice care in an EoL case vignette. Physicians who were more religious had higher odds of viewing withdrawal of life-sustaining treatment more ethically and psychologically challenging than withholding it and had lower odds of agreeing that one should always comply with a competent patient's request to withdraw life-sustaining treatment. Greater research is needed to evaluate how this relationship manifests itself in patient care conversations and shared clinical decision-making in the hospital. **Abstract:** <http://bit.ly/2Elbokd>

N.B. Additional articles on the Islamic perspective on EoL and EoL care noted in 5 & 12 February 2018 issues of Media Watch (#549, p.8 and #550, p.14, respectively).

Palliative care in Australia

The ethics of prioritizing access to palliative care: A qualitative study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 25 February 2019 – Palliative care (PC) services are increasingly required to consider issues of resource management as demand for services increases. The authors sought to explore ethical issues associated with prioritization decisions in PC. Twenty health professionals working across disciplines (primary, specialist; medicine, nursing, and allied health), service types (inpatient, hospital liaison, and community), and locations (metropolitan and rural) in Victoria, Australia, participated in this study. Four themes emerged: 1) Clinicians understood the tension between maintaining service quality with the delivery of a compromised service that sought to respond to demand; 2) They were aware of the influences of relationships and responsibilities upon patient waiting list prioritization; 3) Reported a hierarchy of suffering with certain types of clinical problems viewed as more urgent than others, for example, pain being more urgent than existential distress; and, 4) Clinicians noted a lack of transparency around waiting lists as they currently exist. This study revealed key ethical decision-making issues associated with prioritizing access to PC services. Making explicit the processes and influences upon decision-making provides greater transparency of healthcare utilization at the end of life. **Abstract:** <http://bit.ly/2Ecl4Ja>

Noted in Media Watch 15 October 2018 (#585, pp.10-11):

- *INTERNAL MEDICINE JOURNAL*, 2018;48(10):1173-1174. **'How much end-of-life care is of low value?'** A significant proportion of healthcare expenditure is spent on patients in their last year of life. In the U.S., such patients accounted for 25% of the Medicare budget in 2009, with more recent data from 2009 to 2011 from nine developed countries showing the share of total healthcare spending incurred ranging from 8.5% in the U.S. to 11.2% in Taiwan. In Australia, hospital care for the last year of life for those aged 65 years and over constitutes around 9% of all inpatient costs. A rising concern is how much of this relatively expensive end-of-life care is of low value, that is, ineffective or even harmful. **Full text:** <http://bit.ly/2ExTADS>

Noted in Media Watch 11 June 2018 (#567, p.9):

- *JOURNAL OF CLINICAL PATHWAYS* | Online – 8 June 2018 – **'Are end-of-life care costs actually decreasing?'** It is well documented that healthcare 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:** <http://bit.ly/2Ej4XhM>

TeleHospice: A community-engaged model for utilizing mobile tablets to enhance rural hospice care [in the U.S.]

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 25 February 2019 – In rural communities, providing hospice care can be a challenge. Hospice personnel sometimes travel great distances to reach patients, resulting in difficulty maintaining access, quality, cost-effectiveness, and safety. In 1998, the University of Kansas Medical Center piloted the country's first TeleHospice (TH) service. At that time, challenges with broad adoption due to cost and attitudes regarding technology were noted. A second TH project was launched in early 2017 using newer technology; this article updates that ongoing implementation. From August 2017 through January 2018, 218 TH videoconferencing encounters including 917 attendees occurred. Calls were made for direct patient care, family support, and administrative purposes. These TH calls have been shown to save HSI money, and initial reports suggest they may strengthen the communication and relationships between staff, patients, and the patient's family. Finding innovative, cost-effective, and community-driven approaches such as TH are needed to continually advance hospice care. TeleHospice's potential to supplement and improve hospice services while reducing costs is significant, but continued research is needed to understand best fit within frontier hospices, to inform future urban applications, and to address reimbursement. **Abstract:** <http://bit.ly/2INsufU>

Noted in Media Watch 12 June 2017 (#516, p.8):

- *JOURNAL OF CLINICAL ONCOLOGY*, 2017;15_suppl:e6546. 'TeleHospice: Implementation lessons from rural hospice care with mobile tablets.' Technology advances and a community-centered approach have increased TeleHospice (TH) adoption. With decreasing budgets as well as rural hospice closures, innovative, cost-effective and community-driven approaches such as TH are needed to decrease disparities. [From staff meetings alone, there was a savings of approximately \$2,500/month, with TH staff noting increased morale, by increased team communication.] Continued research is needed to understand best fit within frontier hospices, to inform future urban applications and to address reimbursement. **Abstract:** <http://bit.ly/2IEmdz4>

N.B. Additional articles on the provision and delivery of hospice and palliative care services in rural America noted in 28 January 2019 issue of Media Watch (#599, p.16).

Twelve-step programs and spiritual support at the end of life

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 25 February 2019 – Experts estimate that over 25 million Americans are in recovery from addiction to alcohol and other drugs. Many will be confronted with a serious progressive illness necessitating palliative care or hospice services. In current literature, substance use disorder has mostly been examined in relation to appropriate symptom assessment and management, opioid risk screening, and controlled substance prescribing practices. However, as hospice and palliative care (HPC) clinicians strive to provide whole person care for the seriously ill, awareness and facilitation of healthy psychosocial-spiritual coping strategies for recovering addicts should enhance such care. One of the more common support mechanisms to support recovery is the 12-step program, based on Alcoholics Anonymous. Twelve-step programs have been shown to provide effective coping strategies, not only to help facilitate ongoing abstinence but also to support other psychosocial-spiritual crises. The HPC providers may help to serve those living with addiction disorders better by assessing not only patient histories of substance use/abuse and other addictive behaviors but by facilitating their ongoing support recovery efforts. The authors use two HPC cases to illustrate the value of 12-step recovery programs in patient support and provide recommendations for enhancing such healthy coping in HPC clinical settings. **Abstract:** <http://bit.ly/2U54Ywo>

N.B. Additional articles on HPC services for patients with drug and alcohol addictions noted in 19 November 2018 issue of Media Watch (#590, pp.13-14).



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Utility of the Seattle Heart Failure Model for palliative care referral in advanced ambulatory heart failure

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 27 February 2019 – Physicians face uncertainty when predicting death in heart failure (HF) leading to under-utilisation of palliative care (PC). The authors assessed the Seattle Heart Failure Model (SHFM) as a referral tool by evaluating its performance in predicting 1-year event-free survival from death, heart transplant (HTx), and ventricular assist device (VAD) implantation. 612 patients were included in the study. During the 1-year follow-up, there were 83 deaths, 4 HTx and 1 VAD. Although SHFM showed very good discrimination and adequate calibration in medium to low-risk patients, it underestimated event-free survival by 12% in high-risk patients. SHFM's clinical utility was limited: 33% of eligible patients would have missed the opportunity for referral and only 27% of referred patients would have benefited. Use of SHFM could result in a high proportion of referrals while capturing the majority of patients who may benefit from PC. **Abstract:** <http://bit.ly/2T6xscC>

Noted in Media Watch 25 February 2019 (#603, p.7):

- *JOURNAL OF CARDIOVASCULAR NURSING*, 2019;34(2):e9-e18. **'Healthcare providers' perceived communication barriers to offering palliative care to patients with heart failure: An integrative review.** Ten articles met the authors' full inclusion criteria. Most studies were qualitative or non-experimental studies of good quality. Authors of several studies found that healthcare providers lacked basic knowledge about palliative care (PC) or did not possess sufficient knowledge to effectively provide care. Poor knowledge of PC created a barrier between the provider and the patient. Inadequate education or inexperience in PC led to the resistance of health providers to implementing a palliative approach. **Abstract:** <http://bit.ly/2GMA0Fg>

N.B. Additional articles on PC for patients living with heart failure noted in 21 January 2019 issue of Media Watch (#598, p.7).

Haematologists and palliative care: A multi-centric qualitative study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 26 February 2019 – Patients with haematological malignancies, despite a high level of distress, continue to have less access to palliative care (PC) services. The aim of this study was to identify haematologists' perceptions of PC, as well as barriers to patient referral. Data analysis highlighted four themes: 1) The aim of PC was clearly identified as alleviating severe suffering; 2) PC was identified as a separate specialty, and respondents expressed the need for collaboration; 3) Early intervention was perceived as beneficial to avoid certain situations such as hospitalisation or emergency department visits at the end of life (EoL); 4) The main barrier to PC referral remained the negative connotations associated with the term "palliative," which was overwhelmingly associated with the EoL; haematologists would prefer "supportive care" instead. **Abstract:** <http://bit.ly/2H5PTH2>

N.B. Additional articles on integrating PC in the haematology setting noted in the 4 February 2019 issue of Media Watch (#600, pp.14-15).

Changing perceptions is more important than changing names

BRITISH MEDICAL JOURNAL | Online – 28 February 2019 – Nearly 30 years after the World Health Organization first defined "palliative care," we are no closer to agreeing what the term means. Palliative care (PC) has driven major improvements in the care of people with life limiting illnesses and fostered more open public discourse about death and dying. National and international policies advocate better access to PC for everyone who needs it. *The Lancet* Commission goes further, describing it as a basic human right in the face of unrelieved suffering affecting millions worldwide.¹ The 2018 Astana Declaration endorses PC as an essential component of primary healthcare worldwide: "Promotive, preventive, curative, rehabilitative services, and PC must be accessible to all."² Yet, stigmatisation of the term among patients, professionals, and the public continues to counter positive messages about its benefits. **Introductory paragraph:** <http://bit.ly/2NzLBsA>

Cont.

1. 'Alleviating the access abyss in PC and pain relief: An imperative of universal health coverage,' *The Lancet*, October 2017. [Noted in 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** <http://bit.ly/2Ww8CKu>
2. 'Declaration on Primary Health Care,' Global Conference on Primary Health Care, Astana, Kazakhstan, World Health Organization, October 2018. **Download/view at:** <http://bit.ly/2GOrVAR>

Noted in Media Watch 6 August 2018 (#603, p.4):

- *ADVANCES IN PULMONARY HYPERTENSION*, 2018;17(1):34-35. **'Might rebranding palliative care improve its integration into treatment for those patients diagnosed with pulmonary arterial hypertension?'** A reasonable consideration related to patients with pulmonary arterial hypertension is whether rebranding palliative care (PC) may be an effective measure for increasing early access to PC. The author examines: 1) Is the term "palliative care" opaque and/or associated with negative connotations by physicians, patients, and their families; 2) Is there evidence that an alternative term, such as "supportive care," may be viewed more favorably; and 3) Has rebranding using "supportive care" been adopted by medical centers with improved outcomes? **Full text:** <http://bit.ly/2H6SfW7>

Noted in Media Watch 23 April 2018 (#560, p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 20 April 2018 – **'Increasing information dissemination in cancer communication: Effects of using "palliative," "supportive," or "hospice" care terminology.'** When attempting to share information about comfort-oriented care, many use "palliative," "supportive," and "hospice" care terminology interchangeably, but we lack evidence about the effects of using these different terms. In this study, the terminology used had a large effect. The information labeled as being about "supportive" care was significantly more likely to be selected. If these effects are supported by additional research, there may be low-cost, highly feasible changes in language choice that increase the dissemination of relevant health information. **Abstract:** <http://bit.ly/2NzOFF6>

N.B. Additional articles on terminology in the context of living with a life-threatening or life-limiting illness and end-of-life care noted in 10 September 2018 issue of Media Watch (#580, pp.7-8).

Should doctors cry at work?

BRITISH MEDICAL JOURNAL | Online – 26 February 2019 – Many doctors admit to crying at work, whether openly empathising with a patient or on their own behind closed doors. Common reasons for crying are compassion for a dying patient, identifying with a patient's situation, or feeling overwhelmed by stress and emotion. Probably still more doctors have done so but been unwilling to admit it for fear that it could be considered unprofessional – a sign of weakness, lack of control, or incompetence. However, it's increasingly recognised as unhealthy for doctors to bottle up their emotions. Psychiatry is a specialty in which doctors might view crying as acceptable, says Annabel Price, visiting researcher at the Department of Psychiatry, University of Cambridge, and a consultant in liaison psychiatry for older adults. Having discussed the issue with colleagues before being interviewed for this article, she says that none of them would think less of a colleague for crying at work: "There are very few doctors who haven't felt like crying at work now and again." A situation that may move psychiatrists to tears is finding that a patient they've been closely involved with has died by suicide. "This is often an unexpected tragic event: it's very human to become upset, and sometimes it's hard not to cry when you hear difficult news," says Price. She adds that the possibility of losing control and crying in front of a patient is something medical students often tell her that they feel anxious about. She responds by telling them about the occasions when she's cried at work, how she managed at the time and afterwards, and that it's possible to do this and still be a good [doctor]. **Introductory paragraphs:** <http://bit.ly/2SYInoG>



Would this article be of interest to a colleague?

Withholding or withdrawing life support versus physician-assisted death: A distinction with a difference?

CURRENT OPINION IN ANESTHESIOLOGY, 2019;32(2):184-189. Withholding or withdrawing life-sustaining therapy is generally differentiated from physician-assisted suicide (PAS) or euthanasia based on the distinction between intention and foresight. The distinction between intention and foresight differs from the morally irrelevant distinction between doing and allowing. Intention and foresight may be distinguished by their opposing directions of fit between world and mind. Intention is held to be of greater moral significance than foresight because it guides and constrains our actions, determines the moral quality of our actions, and expresses the moral character of the agent. Opponents of the distinction argue that it undermines moral accountability for foreseen consequences of our actions and is overly concerned with the physician's state of mind rather than the patient's experience. They also argue that intentions may be vague and difficult to express or ascertain. Several reasons may be given in favor of the distinction between intention and foresight. Given this distinction, the moral permissibility of withholding or withdrawing life-sustaining therapy does not necessarily entail the moral permissibility of PAS or euthanasia. **Abstract:** <http://bit.ly/2BZO1fF>

Related

- *ANNALS OF THE AMERICAN THORACIC SOCIETY* | Online – ‘**Explaining the process of determining futility increases lay public acceptance.**’ In this study, providing detailed process information (PI) increased the perceived appropriateness of withholding treatment by approximately 10 percentage points in each vignette: (chemotherapy: 76.3% to 85.6%; dialysis: 68.6% to 79.2%). PI remained associated with appropriateness of withholding treatment after adjustment for order and respondent characteristics... PI had no effect on the emotional response to the cases. Providing process-based conflict resolution information increases public acceptance of determinations of medical futility, supporting the practice outlined in national consensus statements. **Abstract:** <http://bit.ly/2NImKTT>

The role of service factors on variations in place of death [in England]: An observational study

HEALTH SERVICES & DELIVERY RESEARCH | Online – Accessed 27 February 2019 – This is, to date, the largest national population-based evaluation study of the relationship between healthcare services and place of death (PoD). It was found that area-level service factors, including commissioning, type and capacity, location, workforce and service use, do play a role in the PoD. Hospice capacity was associated with a significantly higher chance of hospice death in non-cancer deaths but a slightly lower chance of hospice death in cancer deaths. The distance to the nearest care facility was negatively related to the probability of a patient dying in that care facility. The strength of the association of the service factors with PoD was small overall and there was a significant interactive effect between the service factors and socio-demographic and

clinical variables, suggesting that high-quality end-of-life care (EoLC) needs to be built on a service-level configuration that is tailored to the individual's circumstances. A large data gap was identified, which means that more national data collection is required on services relevant to palliative and EoLC. **Access to full text (via PubMed):** <http://bit.ly/2ECniYj>

Extract from *Health Services & Delivery Research* article

Among the 431,735 adult deaths, hospitals were the most common PoD (47.3%), followed by care homes (23.1%), homes (22.5%) and hospices (6.1%). One-third (30.3%) of the deaths were due to cancer and two-thirds (69.7%) were due to non-cancer causes.

Noted in Media Watch 22 May 2017 (#513, p.11):

- *BMC MEDICINE* | Online – 18 May 2017 – ‘**How many people will need palliative care in 2040? Past trends, future projections and implications for services.**’ By 2040, annual deaths in England & Wales are projected to rise by 25.4% (from 501,424 in 2014 to 628,659). If age- and sex-specific

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proportions with palliative care (PC) needs remain the same as in 2014, the number of people requiring PC will grow by 25% (from 375,398 to 469,305 people/year). However, if the upward trend observed from 2006 to 2014 continues, the increase will be of 42.4% (161,842 more people/year, total 537,240). Healthcare systems must adapt to the age-related growth in deaths from chronic illness by focusing on integration and boosting of PC across health and social care disciplines. **Full text:** <http://bit.ly/2IHcYCi>

Noted in Media Watch 2 December 2013 (#334, p.15):

- *PALLIATIVE MEDICINE* | Online – 29 November 2013 – ‘**End-of-life care and achieving preferences for place of death in England: Results of a population-based survey...**’ 35.7% of respondents reported that the deceased said where they wanted to die, and 49.3% of these were reported to have achieved this. Cancer patients were more likely to achieve preferences than patients with other conditions. Being reported to have a record of preferences for place of death increased the likelihood of dying at home. When rating care in the last two days, respondents were more likely to rate “excellent” or “good” for nursing care, relief of pain and other symptoms, emotional support and privacy of patient’s environment if their relative died in their preferred place. **Abstract:** <http://bit.ly/2H5bjUQ>

Preparedness for caregiving: A phenomenological study of the experiences of rural Australian family palliative carers

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 27 February 2019 – The care of people with life-limiting illnesses is increasingly moving away from an acute setting into the community. Thus, the caregiver role is growing in significance and complexity. The importance of preparing and supporting family caregivers is well established; however, less is known about the impact of rurality on preparedness and how preparedness shapes the caregiving continuum including bereavement. The aim of this study, conducted in 2017, was to explore how bereaved rural family palliative carers described their preparedness for caregiving. Participants were recruited voluntarily through past engagement with a Regional Specialist Palliative Care Consultancy Service in Australia. The experiences of caregivers illustrated a lack of preparedness for the role and were characterised by four major themes: 1) Into the unknown; 2) Into the battle; 3) Into the void; and, 4) Into the good. The unknown was associated with a lack of knowledge and skills, fear, prognostic communication, exclusion, emotional distress and grief experience. Battles were experienced in a number of ways: intrapsychically (existing within the mind), through role conflict and identity; interpersonally with the patient, clinician and family; and systematically (against health, financial and legal systems). The void was felt during isolation in caregiving, in relinquishing the role, in bereavement and in feeling abandoned by service providers. Positive experiences, such as being valued, included and connected to supports, and the fostering of closer relationships and deeper meaning, occurred less frequently but temporarily buffered against negative aspects. Implications from this study for policy and practice centre on the frequent, purposeful and genuine engagement of caregivers. **Abstract:** <http://bit.ly/2SxzJIF>

N.B. Additional articles on the provision and delivery of palliative and end-of-life care in rural and remote regions of Australia noted in 25 February 2019 issue of Media Watch (#603, p.4).

The impact of a community-based serious illness care program on healthcare utilization and patient care experience [in the U.S.]

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 27 February 2019 – Healthcare organizations are expanding community-based serious illness care programs to deliver care for homebound patients. Programs typically focus on home-based primary care or home-based palliative care (PC), yet this population may require both services. The authors developed and evaluated a primary and PC program serving seriously ill older adults, called the Reaching Out to Enhance the Health of Adults in Their Communities and Homes (REACH) program. REACH patients had a 43% reduction in hospital visits and a 25% reduction in emergency department visits. Participants in telephone interviews reported a high-quality care experience and very good quality of communication with REACH providers. A care model that integrates home-based primary care and PC has the potential to reduce health service utilization and enhance the care experience for older patients with serious illness. **Abstract:** <http://bit.ly/2Tp5ibY>

Illness as transformative experience: Implications of philosophy for advance care planning

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 1 March 2019 – Advance care planning (ACP) can be complex and challenging for both patients and family members, and the clinicians who support them. Illness and its treatments often cannot be deeply understood without lived experience. The authors highlight how lived experience can bring about unpredictable changes in an individual's values and preferences. They examine the implications of such “transformative experiences” ... and ... consider consequences for clinical practice and how an understanding of transformative experience might enhance current approaches to ACP. **Abstract (inc. link to references):** <http://bit.ly/2TddNrB>

Related

- *AMERICAN FAMILY PHYSICIAN*, 2019;99(5): 278-280. ‘**To prepare patients better: Reimagining advance care planning.**’ Forty-five million Americans live with one or more serious illnesses, many of which are life-limiting and marked by functional decline. Family physicians (FPs) play a pivotal role in the care of these patients through their deep, longitudinal relationships. One-third of board-certified FPs report using palliative care skills in their practices. Although some view advance care planning (ACP) as a discrete task – a form to be filled out, a decision to be made – the authors suggest thinking about it as an iterative and integrative process. Process-oriented ACP better prepares patients for medical decision-making. **Full text:** <http://bit.ly/2Vt1zrh>
- *AMERICAN FAMILY PHYSICIAN*, 2019;99(5):281-283. ‘**Preparing for serious illness: A model for better conversations over the continuum of care.**’ Clinicians play a critical role in this process by sharing the prognosis, asking patients about what is most important, and making a recommendation grounded in each patient's values and priorities. The Serious Illness Conversation Guide is derived from patient-tested language and best practices in palliative care and suggests open-ended questions that can be adapted for any patient: What are your most important goals if your health situation worsens? What abilities are so critical to your life that you can't imagine living without them? These types of questions expand the dialogue beyond end-of-life procedures. **Full text:** <http://bit.ly/2Tke1aW>
- *BMC PALLIATIVE CARE* | Online – 2 March 2019 – ‘**Assigned nurses and a professional relationship: A qualitative study of COPD patients' perspective on a new palliative outpatient structure named CAPTAIN.**’ A new palliative structure CAPTAIN [Comprehensive And Prospective Treatment and Individual Nursing] supported an individualized professional relationship between patient and nurse and this relationship positively impacted patient's ability to self-manage their life with chronic obstructive pulmonary disease. No topic was too sensitive to discuss... Advance care planning was not perceived as something special or fragmented, but as an integrated part of all dialogues with the health professionals. **Full text:** <http://bit.ly/2tNmFEY>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 March 2019 – ‘**Illness as transformative experience: Implications of philosophy for advance care planning.**’ Advance care planning (ACP) can be complex and challenging for both patients and family members, and the clinicians who support them. Illness and its treatments often cannot be deeply understood without lived experience. The authors highlight how lived experience can bring about unpredictable changes in an individual's values and preferences. They examine the implications of such “transformative experiences” ... and ... consider consequences for clinical practice and how an understanding of transformative experience might enhance current approaches to ACP. **Abstract (inc. link to references):** <http://bit.ly/2TddNrB>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 February 2019 – ‘**Cancer patients' preferences [in Japan] for phrases in end-of-life discussions.**’ In this study, cancer patients assessed their own preferences for phrases with/without additional reassurance statements, e.g., statements of “hope for the best and prepare for the worst” ... when discussing prognosis; symptom palliation when discussing code status; and, specific goals, continuity of care, and non-abandonment when discussing hospice referral. Cancer patients systematically preferred reassurance statements. In end-of-life discussions, especially with patients with task-oriented coping, clinicians may provide additional reassurance statements. **Abstract (w. link to references):** <http://bit.ly/2Tj5cCN>

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- *PALLIATIVE CARE: RESEARCH & TREATMENT*: Online – 27 February 2019 – ‘**Advance care planning in dementia: Recommendations for healthcare professionals.**’ The process of advance care planning in dementia is far from straightforward; as dementia progresses, the ability to consider future thoughts and actions becomes compromised, thus affecting decision-making abilities. Family carers find themselves increasingly in a position where they need to inform, or directly make, decisions on behalf of the person with dementia. This article discusses the context and importance of a palliative care approach and recommends rationales and strategies for healthcare professionals to support families affected by dementia to better plan for their future care. **Full text:** <http://bit.ly/2HabdvD>

N.B. Additional articles on ACP, advance directives and end-of-life decision-making for people living with Alzheimer’s disease and other forms of dementia noted in 18 February 2019 issue of Media Watch (#602, pp.8-9).

Chronic pain, functional status, and life satisfaction are associated with patients living with HIV discussing advanced care planning with their family or friends

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 25 February 2019 – In the era of effective antiretroviral therapy, persons living with HIV/AIDS (PLWHA) are living longer, transforming HIV into a serious chronic illness, warranting discussions between patients and their loved ones about advanced care planning (ACP). Evidence is needed on factors associated with patients’ likelihood to discuss ACP with loved ones. To further characterize factors associated with successful ACP in PLWHA with their loved ones, the authors examined associations between patients having ACP discussions with the need for assistance with personal care, chronic pain, life satisfaction, prior family disagreements over healthcare decisions, sex, age, and interference in daily routines due to memory problems. Slightly more than half of survey respondents discussed ACP with loved ones (57%). Higher levels of chronic pain, needing assistance with personal care, greater life satisfaction, prior family arguments over healthcare decisions and female sex were associated with higher odds of discussing ACP with loved ones, while age, drug use, education level, depression, and memory problems were non-significant. These results suggest that interventions to increase ACP among PLWHA and their loved ones should target males. **Abstract (w. link to references):** <http://bit.ly/2ThxVlc>

Noted in Media Watch 3 September 2018 (#579, p.6):

- *AIDS CARE* | Online – 25 August 2018 – ‘**Caregiving preferences and advance care planning among older adults living with HIV.**’ Logistic regression analyses were modeled to determine the characteristics associated with: 1) Preference for formal short-term care; 2) Preference for formal long-term care; 3) Having at least one contact for emergency care; 4) Having an advance directive or living will; and, 5) Having a healthcare proxy or agent. Findings suggest that older adults living with HIV prefer informal sources of support for their caregiving needs despite having small social networks and individuals with limited social networks are particularly vulnerable due to lack of access to caregivers in sudden or unexpected health situations. **Abstract (w. link to references):** <http://bit.ly/2NBzsDT>

Psychedelics and dying care: A historical look at the relationship between psychedelics and palliative care

JOURNAL OF PSYCHOACTIVE DRUGS | Online – 1 March 2019 – This article examines the historical relationship between psychedelics and palliative care (PC). Historians have contributed to a growing field of studies about how psychedelics have been used in the past, but much of that scholarship focused on interrogating questions of legitimacy or proving that psychedelics had therapeutic potential. PC had not yet developed as medical sub-specialty, more often leaving dying care on the margins of modern, pharmaceutical-based treatments. As psychedelic researchers in the 1950s began exploring different applications for psychoactive substances such as LSD and mescaline, however, dying care came into clearer focus as a potential avenue for psychedelics. Before that application gained momentum in clinical or philosophical discussions, psychedelics were criminalized and some of those early discussions were lost. This article looks back at historical discussions about LSD’s potential for easing the anxiety associated with dying, and considers how those early conversations might offer insights into today’s more articulated discussions about psychedelics in PC. **Abstract:** <http://bit.ly/2Ta1k7V>

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Noted in Media Watch 29 January 2018 (#548, p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 January 2018 – ‘**Taking psychedelics seriously.**’ Even with an expanding evidence base confirming safety and benefits, political, regulatory, and industry issues impose challenges to the legitimate use of psychedelics. Given the prevalence of persistent suffering and growing acceptance of physician-hastened death as a medical response, it is time to revisit the legitimate therapeutic use of psychedelics. This paper overviews the history of this class of drugs and their therapeutic potential. Clinical cautions, adverse reactions, and important steps related to safe administration of psychedelics are presented, emphasizing careful patient screening, preparation, setting and supervision. **Abstracts:** <http://bit.ly/2tOtJBa>

Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation

Patients’ views on care and their association with outcomes in palliative care

PALLIATIVE MEDICINE | Online – 1 March 2019 – In palliative care (PC), we often rely on the accounts of bereaved relatives to report the quality of end-of-life care, and there are no validated patient-reported measures of the experience of care. The authors report therefore on a new questionnaire, Views on Care, to address this gap. It consists of four questions ... selected/refined from St Christopher’s Index of Patient Priorities (SKIPP),¹ which address patients’ evaluation of: 1) Change in their main concerns,; 2) Benefit from palliative services; 3) Previous and 4) Current quality of life... First, it is important to note that most participants reported that things were getting better and that PC was providing benefit. This was found across different settings and palliative Phases of Illness. Second, patients reported positive change more often when physical (rather than overall, psychological or communication/practical) outcomes had improved. Third, the authors found that reports of positive impact of the PC teams was associated with improvement in communication/practical outcomes, but not with improvement in outcomes overall. This is an important finding as it demonstrates how much communication and practical matters influence the experience of care. It also illustrates that both outcomes and experience need to be measured if quality of care is to be properly understood. **Full text:** <http://bit.ly/2EIZd6J>

1. ‘Development and initial validation of a new outcome measure for hospice and PC: The St. Christopher’s Index of Patient Priorities (SKIPP),’ *BMJ Supportive & Palliative Care*, published online 16 September 2013. [Noted in the 23 September 2013 issue of Media Watch (#324, p.9)] **Abstract:** <http://bit.ly/2Tu6viA>

Clinicians’ perceptions of opioid error: Contributing factors in inpatient palliative care services: A qualitative study

PALLIATIVE MEDICINE | Online – 1 March 2019 – Opioid errors are a leading cause of patient harm and adversely impact palliative care (PC) inpatients’ pain and symptom management. Yet, the factors contributing to opioid errors in PC are poorly understood. Identifying and better understanding the individual and system factors contributing to these errors is required to inform targeted strategies. A total of 58 clinicians participated in eight focus groups and 20 semi-structured interviews. Contributory factor domains were identified, including: 1) Active failures; 2) Task characteristics of opioid preparation; 3) Clinician inexperience; 4) Sub-optimal skill mix; 5) Gaps in support from central functions; 6) The drug preparation environment; and; 7) Sub-optimal clinical communication. This study identified multiple system-level factors contributing to opioid errors in inpatient PC services. Any quality and safety initiatives targeting safe opioid delivery in specialist PC services needs to consider the full range of contributing factors, from individual to systems/latent factors, which promote error-causing conditions. **Abstract:** <http://bit.ly/2XvH0fQ>

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Noted in Media Watch 11 May 2018 (#563, p.11):

- *SUPPORTIVE CARE IN CANCER* | Online – 4 May 2018 – ‘**Clinicians’ perceptions of medication errors with opioids in cancer and palliative care services: A priority setting report.**’ Participants in this study took part in a series of workshops and, drawing on actual incidents occurring in their services, sought to identify where in the opioid medication process errors were most frequently occurring. Opioid error types and perceived contributing factors were explored, and strategies to reduce/ prevent opioid errors were proposed. The priority setting process provided valuable insights into the types of opioid errors that occur in cancer and PC services and the complexity of addressing opioid errors from the clinician’s perspective. **Abstract (inc. list of references):** <http://bit.ly/2VwbTyY>

N.B. Additional articles on medication errors in PC noted in 26 February 2018 issue of Media Watch (#552, p.15).

Preferences regarding and communication about end-of-life care among older Iranian-American adults

WESTERN JOURNAL OF NURSING RESEARCH | Online – 22 February 2019 – This article addresses end-of-life (EoL) care for older Iranian-American adults. The purposes are twofold: 1) To explore participants’ preferences for home or hospital care in the event they face EoL conditions; and, 2) To learn how participants prefer to communicate these preferences. Results showed that about half of the 130 participants had communicated their EoL care preferences through written documents and/or verbal discussions. A set of factors predicted the preferences and communications. Higher scores of social support and greater numbers of cohabitants were associated with a preference for home care, and experience of a loved one’s death was associated with participants being willing to communicate their preferences for type of care. This study can bridge the gap between culturally diverse older adults’ preferences and types of EoL care they ultimately receive. **Abstract:** <http://bit.ly/2XnALuz>

Experiential palliative care immersion: Student nurse’s narratives reflect care competencies

WESTERN JOURNAL OF NURSING RESEARCH | Online – 19 February 2019 – Palliative care (PC) leaders have devised primary palliative nursing care competencies – Competencies & Recommendations for Educating undergraduate nursing Students (CARES) – that all students should achieve. Nursing students participated in an innovative PC immersion experience, the Comfort Shawl Project. Four CARES-related categories were analyzed: 1) Individual values and diversity; 2) Compassionate communication; 3) Fostering quality of life; and, 4) Self-insight and emotion. Reflections were highly representative of recognizing individual values and diversity, representing sensitivity for patients’ unique differences in values, an integral component of PC. The Comfort Shawl Project shows promise as an experiential immersion for introducing nursing students to CARES competencies. **Abstract:** <http://bit.ly/2SrhgNY>

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 26 February 2019 – ‘**Resilience in inpatient palliative care nursing: A qualitative systematic review.**’ Palliative care (PC) nursing is more stressful if patients or situations remind nurses of personal experiences. Nurses cope better with adequate support; however, coping does not necessarily imply increased resilience. Resilience occurs when nurses cognitively process their experiences, articulate their thoughts and feelings into a coherent narrative, and construct a sense of meaning or purpose. Future research could explore how nurses understand resilience and how it could be enhanced in the PC inpatient setting. With resilience, nurses may remain in the profession longer and improve the quality of care when they do. **Abstract:** <http://bit.ly/2XttkCa>



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 p.19.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BRITISH MEDICAL JOURNAL* | Online – 28 February 2019 – **Commentary on ‘Fear of assisted dying: could it lead to euthanasia on demand or worsen access to palliative care?’**¹ A recent article commissioned by the *British Medical Journal* was presumably an attempt by the journal to present a balanced view of the assisted dying debate. The article is liberally sprinkled with references to news articles, while the selection of facts is incoherent and patchy. For example the author points out a slowing of Dutch euthanasia numbers in the first nine months of last year, ignoring the 311% increase in the last decade, the 320% increase in Oregon over the same period or the 24% increase in just six months in Canada in 2017. The author claims that in the U.S. cost savings of assisted dying would be “very low,” but the paper she quotes suggests savings of \$627 million U.S. back in 1995, which is the equivalent of \$1,036 million U.S. in today’s values. A more recent evaluation in Canada estimates that assisted dying would reduce annual healthcare spending by between \$34.7 and \$138.8 Canadian. No government or health economist is going to ignore such savings. The author mentions the current controversy in The Netherlands over patients with advanced dementia and psychiatric conditions, quoting the 2017 report stating there were only 3 patients with advanced dementia and 83 with psychiatric conditions. What she does not mention is that the same report includes 166 cases of early stage dementia, 293 with “multiple geriatric syndromes,” which includes “cognitive deterioration,” 782 cases which had a combination of conditions that included dementia and psychiatric conditions, or the 13 cases of 18-40 years old individuals with a psychiatric disorder. The article is not the cohesive, structured, referenced and factual contribution that is expected in the *BMJ*. **Full text:** <http://bit.ly/2Uf4wvx>
 1. ‘Fear of assisted dying: could it lead to euthanasia on demand or worsen access to palliative care?’ *British Medical Journal*, published online 26 February 2019. **Introductory paragraphs:** <http://bit.ly/2UfAtE1>
- *HEALTH & SOCIAL WORK* | Online – 23 February 2019 – **‘Social work practice with medical assistance in dying: A case study.’** Medical assistance in dying (MAiD) recently became legal in Canada, and social workers have an integral role providing psychosocial care to those considering this end-of-life care option. Research has found that most requests for assisted dying have a psychosocial dimension. Social workers are uniquely equipped to understand the personal and contextual factors informing the choice for MAiD and offer supports. A case example highlights practice opportunities for social workers throughout the MAiD process. **Abstract:** <http://bit.ly/2lwgRdg>
- *MEDICAL ANTHROPOLOGY QUARTERLY* | Online – 27 February 2019 – **‘Care as an alternative to euthanasia? Reconceptualizing veterinary palliative and end-of-life care.’** Palliative care (PC) is routinely offered to humans in the U.K., while euthanasia remains illegal. The converse is true for non-human animals (henceforth animals). Indeed, euthanasia is widely accepted as the appropriate course of action for “suffering” animals, and for those whose behaviors or suspected ill health are thought to pose a threat to others. This article details examples of non-human death at a multi-faith ashram whose members vehemently oppose all forms of killing on religious grounds. Through exploring their efforts in PC for animals, and their emphasis on natural death as a means of respecting the sanctity of life, the practical, emotional, and theoretical viability of caring for, instead of killing, other animals at the ends of their lives is considered. In the process, normative distinctions between different categories of animals, (including humans), and different approaches to end-of-life care (PC, euthanasia, natural death) are called into question. Indeed, paying mindful attention to the diverse ways in which individual animals are cared for as they die reveals the potential violence inherent in both PC leading to natural death, and euthanasia, blurring perceptions of good and bad death in both veterinary and human medicine. **Abstract:** <http://bit.ly/2IKcb3E>
- *MEDICAL JOURNAL OF AUSTRALIA* | Online – 25 February 2019 – **‘Victoria’s voluntary assisted dying law: Clinical implementation as the next challenge.’** The Voluntary Assisted Dying Act 2017 (Vic) (VAD Act) will become operational on 19 June 2019. A designated 18-month implementation period has seen an Implementation Taskforce appointed, and work is underway on projects including developing clinical guidance, models of care, medication protocols and training for doctors participating in voluntary assisted dying (VAD). While some have written on the scope of, and reaction to, the VAD legislation, there has been very little commentary on its implementation. Yet, important choices must be made about translating these laws into clinical practice. These choices have major implications for doctors and other health professionals (including those who choose not to facilitate VAD), patients, hospitals and other health providers. This article considers some key challenges in implementing Victoria’s VAD legislation. **Full text:** <http://bit.ly/2ErXKMq>

Publishing Matters

Big pharma is embracing open-access publishing like never before

NATURE | Online – 28 February 2019 – In a literature analysis,¹ researchers found that the proportion of open-access papers published by 23 large drug companies ... almost doubled between 2009 and 2016, and has overtaken the proportion of freely available papers published generally in medicine-related fields. The researchers classified each paper according to whether or not it was open access. To see how this compared with the medical literature more generally, they also examined all publications in medicine-related categories – including those that didn't have industry authors. The authors found that in 2009, the proportion of open-access papers published by drug companies was just over 20% – lower than the 29% found in the medical literature baseline... But over the next 7 years the percentage of open-access papers from the industry steadily increased to more than 40% in 2016, the first year in which it exceeded the proportion of open-access articles in the general medical literature. As well as producing more freely available papers, industry is consuming more of them. The percentage of open-access papers cited in industry publications rose from 35% in 2009 to around 47% in 2016. During this period, the proportion of open-access papers cited in the general literature remained at around 33%. But the authors only looked at papers published since 2009, which represent only a fraction of all cited publications. The researchers also found that industry and non-industry authors published more of their open-access papers through the “green” route, in which a scientist makes a paper available in a repository..., rather than through the “gold” route, in which a paper can be accessed freely from a publisher. The proportion of gold papers has increased considerably in the past few years, but industry lags behind this general trend. **Full text:** <https://go.nature.com/2BYA9SK>

1. 'Production and uptake of open access publications involving the private sector: The case of big pharma,' Proceedings of the 23rd International Conference on Science & Technology Indicators, February 2019. **Abstract:** <http://bit.ly/2T6wQUc>

Avoiding predatory journals: Quick peer review processes too good to be true

NURSING FORUM | Online – 25 February 2019 – Nursing is experiencing the growth of predatory journals with questionable peer review processes. These journals publish submissions quickly and do not enhance the authors' reputation and scholarship of nursing. A qualitative, descriptive study design examined the legitimacy of the peer-review process described on the websites of predatory nursing journals. Posted review processes were examined for quality indicators related to language use, author control, and transparency. Of the 53 predatory nursing journals describing a peer-review process, the majority indicated that all submitted content was sent for peer review. Most journals did not describe the criteria on which submitted articles would be evaluated. Quality indicators for language included multiple grammatical errors and odd language and phrases. Author control of tracking, revisions, and review of galley proofs were inconsistent in the described peer-review processes. The majority did not provide a way to track a manuscript through the process. Most journals did not explain the types of peer review they conducted. Authors can sidestep the trap of publishing in predatory journals by paying attention to the peer review process when selecting a journal for publication. **Abstract:** <http://bit.ly/2BY0u3E>

Guidelines for open peer review implementation

RESEARCH INTEGRITY & PEER REVIEW | Online – 27 February 2019 – Open peer review (OPR) is moving into the mainstream, but it is often poorly understood and surveys of researcher attitudes show important barriers to implementation. As more journals move to implement and experiment with the myriad of innovations covered by this term, there is a clear need for best practice guidelines to guide implementation. This article has aimed to address this knowledge gap, reporting work based on literature research, expert interviews and an interactive stakeholder workshop to create best-practice guidelines for

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editors and journals who wish to transition to OPR. The guidelines offer practical and pragmatic advice to these purposes at both a general level and for specific OPR traits. Main points of guidance are: 1) Set open peer review goal(s); 2) Listen to research communities; 3) Plan technologies and costs; 4) Be pragmatic in approach; 5) Further communicate the concept; and, 6) Evaluate performance. **Full text:** <http://bit.ly/2SAgXjK>

A walk on the wild side: “Predatory” journals and information asymmetries in scientific evaluations

RESEARCH POLICY, 2019;48(2):462-477. In recent years the academic world has witnessed the mushrooming of journals that falsely pretend to be legitimate academic outlets. The authors study this phenomenon using information from 46,000 researchers seeking promotion in Italian academia. About 5% of them have published in journals included in the blacklist of “potential, possible, or probable predatory journals” elaborated by the scholarly librarian Jeffrey Beall. Data from a survey that they conducted among these researchers confirms that at least one third of these journals do not provide peer review or they engage in some other type of irregular editorial practice. The authors identify two factors that may have spurred publications in dubious journals. First, some of these journals have managed to be included in citation indexes such as Scopus that many institutions consider as a guarantee of quality. Second, authors who publish in these journals are more likely to receive positive assessments when they are evaluated by (randomly selected) committee members who lack research expertise. Overall, analysis suggests that the proliferation of “predatory” journals reflects the existence of severe information asymmetries in scientific evaluations. **Abstract:** <http://bit.ly/2Ue8u7N>

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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Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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

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CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

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ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

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HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RgTvYr>

U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

United States

NEBRASKA | Center for Health Policy & Ethics, Creighton University: <http://bit.ly/2DAED3f>

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Closing the Gap Between Knowledge & Technology

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