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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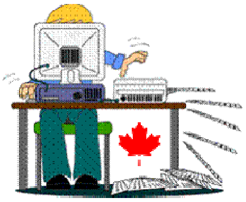

Compiled & Annotated by Barry R. Ashpole

'Has the [U.K.'s] National Health Service Long Term Plan forgotten we are all going to die?' (p.13), in *The Lancet*.

Canada

Appeal court to issue ruling in Ontario family's brain death legal battle

ONTARIO | *The Globe & Mail* (Toronto) – 11 February 2019 – The Ontario Court of Appeal has elected to issue a decision for a case that challenges the legal definition of death – though the central figure in that case, a woman on life support whose parents challenged her diagnosis of brain death, succumbed to cardiac arrest in late December. Taquisha McKitty was 27 years old when she overdosed on a potent cocktail of drugs; six days later, at Brampton Civic Hospital, doctors declared her brain dead. But Ms. McKitty's Christian parents believed as long as their daughter's heart was beating, even with medical assistance, she was still alive. The two perspectives proved irreconcilable, and a legal battle was launched between physician and family over what constitutes death, and who decides when that line has been crossed. There is no clear legislative answer to those questions across much of Canada – they pit science versus faith, prompt examinations of Charter rights and challenge the role of cultural practices in modern medicine. Most Canadian provinces and territories lack a statutory definition of death. The determination is left up to physicians, based on either a stopped heart or a deceased brain. The idea of brain death can be incongruous with the beliefs of some Christian, Muslim, Orthodox Jew and other groups. https://tgam.ca/2E75S5Q

Specialist Publications

'Do family health clinics provide primary-level palliative care in Ontario and the eastern regions of Quebec?' (p.8), in *Canadian Family Physician*.

'Barriers to staff involvement in end-of-life decision-making for long-term care residents with dementia' (p.8), in *Canadian Journal on Aging*.

'Paramedics providing palliative care at home: A mixed-methods exploration of patient and family satisfaction and paramedic comfort and confidence' (p.9), in *Canadian Journal of Emergency Medicine*.

'Community-based specialist palliative care teams and health system costs at end of life: A retrospective matched cohort study' (p.10), in *CMAJ Open*.

Cont.

Noted in Media Watch 17 December 2018 (#594, p.1):

- ONTARIO | *The Globe & Mail* (Toronto) – 12 December 2018 – **'Ontario family's legal fight to keep daughter on life support could change how death is defined across Canada.'** Ontario has no statutory definition of death; nor do most Canadian provinces and territories. The determination is instead left up to physicians. Doctors use one of two sets of criteria to declare a patient dead: either a stopped heart or a deceased brain. Some Christians, Muslims, Orthodox Jews and members of other religions feel that "brain death" doesn't align with their definition of life's end, especially if technology can preserve tissue, send swells of air into lungs and keep a heart beating. https://tgam.ca/2SPmp6F

N.B. Selected articles on the ethical and legal aspects of determination of brain death noted in this issue of Media Watch.

U.S.A.

A patient's guide to pancreatic cancer

U.S. NEWS & WORLD REPORT | Online – 11 February 2019 – According to the American Cancer Society (ACS), pancreatic cancer accounts for about 3% of all cancers in the U.S. and about 7% of all cancer deaths. In 2019, the ACS estimates about 56,770 people (29,940 men and 26,830 women) will be diagnosed with pancreatic cancer, and about 45,750 people (23,800 men and 21,950 women) will die of pancreatic cancer. On average, 1 in 63 men will develop pancreatic cancer in his lifetime. The risk is about 1 in 65 for women. However, each person's odds of getting pancreatic cancer are affected by various risk factors. Unfortunately, pancreatic cancer can be successfully treated only in its earliest stages, before it has spread, so that it can be completely removed by surgery. If the cancer has spread, palliative care can help maintain a higher quality of life by controlling the symptoms and treating the complications of the disease. http://bit.ly/2N4Y5bC

Specialist Publications

'Interdisciplinary teams and home-based medical care: Secondary analysis of a national survey' (p.12), in *Journal of Post-Acute & Long-Term Care Medicine*.

'Minority patient preferences, barriers, and facilitators for shared decision-making with health care providers in the U.S.: A systematic review' (p.16), in *Patient Education & Counseling*.

'*Medscape* Psychiatrist Ethics Report 2018' (p.17), in *Medscape*.

'Measuring mercy: Protecting patient discretion in terminal care under the Fourteenth Amendment' (p.17), in *National Lawyer's Guild Review*.

'Factors affecting California college students' attitudes toward assisted dying' (p.17), in *Omega – Journal of Death & Dying*.

Noted in Media Watch 4 February 2019 (#600, p.7):

- *BMC PALLIATIVE CARE* | Online – 28 January 2019 – **'Timing of palliative care referral and aggressive cancer care toward the end-of-life in pancreatic cancer: A retrospective, single-center observational study.'** The authors' findings mirror the results of a small number of international studies and reaffirm the benefits of early referral to palliative care for pancreatic cancer patients to avoid futile treatment and inappropriate care toward the end of life (EoL). They however question the current benchmarks for aggressive cancer care at the EoL, based on their findings that patients with significant symptoms and whose caregivers lack support appropriately require acute hospital service utilization or care in a supported environment. at are compatible with patient and family needs, informed views, experiences and healthcare priorities. **Full text:** http://bit.ly/2UrUyXw

N.B. Additional articles on palliative and end-of-life care for people living with pancreatic cancer noted in 12 November 2018 issue of Media Watch (#589, p.15).

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Serious health concerns missed in older adults

SCIENCE DAILY | Online – 8 February 2019 – Researchers [engaged in the National Health & Aging Study] examined the prevalence and impact of six common symptoms (pain, fatigue, depression, anxiety, breathing difficulty, sleep problems) and found that nearly half of adults ages 65 and older have two or more of these symptoms and one-fourth have three or more.[1] But often clinicians miss these symptoms, and the more serious health issues they portend because patients only talk about one of these symptoms during a visit. The U.S. is home to almost 50 million adults 65 and older, and this number is expected to grow to 95 million by 2060, according to the U.S. Census Bureau. Today there are only 7,200 geriatricians and 6,400 palliative care physicians, and less than 1% of registered nurses specialize in geriatrics or palliative care, according to research cited in the editorial. http://bit.ly/2TNOusb

Extracts from the National Health & Aging Trends Study

Palliative care (PC) approaches to symptom management that are used effectively in end-of-life (EoL) care could potentially be applied in primary care settings, although the sensitivity analyses demonstrate that the effects of co-occurring symptoms are not limited to the EoL period.

Although it is widely accepted that treating symptoms is important to improving quality of life at the EoL (i.e., PC), there is less appreciation for the potential predictive value of multiple, co-occurring symptoms in the general older adult population.

1. 'Symptom burden among community-dwelling older adults in the U.S.,' *Journal of the American Geriatric Society*, 2019;67(2):223-231. **Full text:** http://bit.ly/2BBw72K

International

Seven in 10 Brits have made no plans for end-of-life care

U.K. | *Your Money* – 15 February 2019 – A survey of more than 3,000 people carried out by Which? found that 71% of people have no plans in place whatsoever for end-of-life care (EoLC).[1] Of the 29% who did, only three in 10 had prepared a living will or advance decision, outlining the types of medical treatment they would refuse if they did not have the capacity to communicate their decisions. The most common step that had been taken, cited by 93% of the sample, was to write a will outlining what should happen to their property, possessions and money after death. Meanwhile, six in 10 had organised Power of Attorney, a legal document that appoints one or multiple "attorneys" to make decisions on your behalf, should they lose mental capacity. 58% had discussed their EoLC preferences with family or friends. The research also revealed a lack of awareness of how hospices can help with EoLC. Only 31% of the sample correctly believed that hospice care is free for all, while 17% thought that patients needed to pay for care in a hospice. As hospice care is paid for through a combination of National Health Service funding and public donations, care provided by a hospice is free for patients and their families. http://bit.ly/2V26HTe

Specialist Publications

'Development and validation of a French questionnaire concerning patients' perspectives of the quality of palliative care: The QUALI-PALLI-Patient' (p.7), in *BMC Palliative Care*.

'Palliative care specialists in hospice and hospital/community teams [in London, England] predominantly use low doses of sedative medication at the end of life for patient comfort rather than sedation: Findings from focus groups and patient records for I-CAN-CARE' (p.14), in *Palliative Medicine*

1. 'Here's why you should plan for your end-of-life care,' Which? 15 February 2019. **Download/view at:** http://bit.ly/2TRagvp

Greater support for [Singapore's] caregivers, seniors

SINGAPORE | *The Straits Times* – 14 February 2019 – A Caregiver Support Action Plan will be rolled out to better help those looking after the elderly and infirm as the population ages and Singaporeans live longer. The Ministry of Health (MOH) held 19 focus group discussions involving over 200 people from last September to get a sense of these caregivers' needs and concerns. Senior Minister of State for Health Edwin Tong announced plans that MOH and partner agencies will embark on in five broad areas, including home-based respite option for caregivers of end-of-life patients. This service will be piloted for cancer patients receiving palliative care at home from mid-2019… http://bit.ly/2tnJn6z

Palliative Care Australia launches roadmap for the future

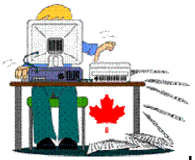
AUSTRALIA | *Australian Ageing Agenda* – 12 February 2019 – A policy proposal has been launched to provide a roadmap for meeting the increasingly complex palliative care (PC) needs of older Australians. 'Palliative Care 2030: Working Towards the Future of Quality Palliative Care for All,' released by Palliative Care Australia (PCA), outlines what the government and communities can do to improve access to PC. It acknowledges there needs to be collaboration, commitment and innovation to meet the PC needs of seniors by 2030. Key policy proposals include: 1) Implementing a whole of government approach to improving PC; 2) Investing in a national PC workforce strategy and providing scholarships for health professionals to complete PC training; 3) Reviewing the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme schedules for PC items to improve access; 4) Educating the community by investing in a PC communications campaign; and, 5) The National Health & Medical Research Council and Medical Research Future Fund provide funding towards nationally significant research programs improving grief and bereavement support for families and carers. PCA board chair Dr Jane Fischer said the guide is a platform to raise discussions that need to occur to meet PC needs of older Australians in the future. The number of deaths each year for people 65-plus is projected to increase from 160,000 in 2018 to more than 200,000 in 2030. http://bit.ly/2SFGSLd

Study finds end-of-life care being left to chance

AUSTRALIA | *Community Care Review* – 12 February 2019 – More than two thirds of older Australians have not left any legally recognised instructions about their end-of-life care for when they are unable to make their own medical decisions, and half have left no directions at all, according to new research.[1] The study by Advance Care Planning Australia (ACPA), which reviewed records of 2,285 people from 51 hospitals, aged care facilities and GP clinics across six states and territories, is the first to provide comprehensive information about the prevalence of advance care directives (ACDs) in Australia. Data was collected between September 2017 and January 2018. It found that only 30% of people had an ACD, or a structured and signed legal document. Twenty 20% had other forms of informal documentation. The odds of having an ACD were lower in hospitals and general practices than in residential care facilities. http://bit.ly/2IaeoVL

1. 'Prevalence and correlates of advance care directives among older Australians accessing health and residential aged care services: Multicentre audit study,' *BMJ Open*, published online 15 January 2019. **Full text:** http://bit.ly/2BwFYqp

N.B. A link to the Palliative Care Australia "roadmap," is embedded at the foot of the *Australian Ageing Agenda* article.



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

Draft law on palliative care to be discussed at large parliamentary hearings in [Russia's] State Duma

RUSSIA | Russian News Agency (Moscow) – 11 February 2019 – Deputies, together with experts, representatives of civil society institutions and regions discuss proposals for amendments to the draft law on palliative care (PC). One of the key issues will be the implementation of the proposed norms. Representatives of over 60 regions, PC specialists, hospice staff, and volunteers are taking part in the discussion. Considering the significance of the bill, it had previously been proposed to consider the preparation of government by-laws necessary for its implementation… A government bill adopted on first reading expands the concept of PC and establishes the patient's right to pain relief, including "heavy medications." The definition of PC is expanding and becoming complex: in addition to direct medical intervention, it includes the provision of psychological assistance to the terminally ill... All this should be aimed at improving the quality of life and getting rid of pain, alleviating other severe manifestations of the disease and maintaining the body's functions. The Law on the Basics of Health Protection is complemented by provision that the patient can count on pain relief, including narcotic and psychotropic drugs. An important innovation concerns the possibility of providing PC at home and in a day hospital residency. It also establishes the right of terminally ill patients to receive medicine free of charge not just in inpatient facilities, as was the case previously, but also in day hospital residency, according to registration. http://bit.ly/2DtoETn

Russian children's ombudsman presses palliative care standard approval

RUSSIA | Russian Legal Information Agency (Moscow) – 11 February 2019 – Russian children's rights commissioner Anna Kuznetsova pushed for approval of an effective palliative care (PC) standard during the State Duma parliamentary hearings held in connection with a PC bill review. Moreover, Kuznetsova considers it necessary to include support service for families of dying patients in the PC concept. According to the ombudsman, PC infrastructure is developed only in 19 regions of Russia. Thus, a standard or a model of the effective PC should be passed to speed up its development in other territorial subjects, she said. Earlier, the State Duma passed the PC draft law in the first reading. The bill specifies the concept of PC and confirms the right of terminal patients to pain relief including drug preparations. http://bit.ly/2DowTju

Noted in Media Watch 8 October 2018 (#584, p.19):

- *PROBLEMY SOTSIAL'NOI GIGIENY, ZDRAVOOKHRANENIIA I ISTORII MEDITSINY*, 2018;28(1):32-35. **'The analysis of results of sociological survey concerning attitude to palliative care support in the Russian Federation.'** Palliative care (PC) has been a regulatory determined form of medical care in Russia since 2011. Until now, no complex analysis was applied to problems occurring during provision of this form of care. This study provides analysis of the results of a survey of with the purpose of determining public demand for development of PC in Russia. **Abstract:** http://bit.ly/2UW7nJR

  N.B. Russian language article.

Noted in Media Watch 15 September 2014 (#375, p.9):

- *БЮЛЛЕТЕНЬ МЕДИЦИНСКИХ ИНТЕРНЕТ-КОНФЕРЕНЦИЙ* | Online – Accessed 10 September 2014 – **'Palliative medicine: Overview and statistics.'** Palliative care (PC) developments are now said to be under way, mostly in the hospital context, in all the regions of Russia. Yet the economic constraints of the 1990s have left health services chronically under-funded. In what is the largest geographic country of the world, the combined hospice and PC services are currently estimated at around 125 and the challenges are acknowledged as considerable. **Abstract:** http://bit.ly/2SAcqlJ

  N.B. Russian language article.

Closing the Gap Between Knowledge & Technology
http://bit.ly/2DANDFB

More and more people opting to pass away at home

SWITZERLAND | Swissinfo.com (Bern) – 11 February 2019 – The treatment and comfort offered dying people in Switzerland could yet be improved, according to newly-published research. In a new report[1] … the researchers found that four out of five people die in hospitals or care homes – places often ill-equipped for treating the dying, and which do not always take account of their needs. More and more people wish to pass away at home, the researchers found: the demand for home care is rising strongly. But such care can be costly and is not reimbursed by basic insurance coverage. The families of those who die at home often end up exhausted. The overall conclusion of the study was that palliative nursing facilities need to be boosted, without forgetting that the end of life (EoL) period can only be planned and controlled to a certain extent. "Timely palliative treatment should be a given for the care and treatments planned during the EoL period," the researchers write. http://bit.ly/2E3FCcu

1. At the time of the publication of this issue of Media Watch, the source of 'Death in Switzerland: Individual and societal perspectives' could not be traced.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Economist* – 12 February 2019 – **'British doctors move to end their opposition to assisted dying.'** The Royal College of Physicians is surveying its 35,000 members on whether to back changes to the law on assisted dying, which is illegal in Britain. Five years ago 44% of them voted against and 25% in favour (the rest were neutral). Under the rules then, the plurality of votes against changing the law was enough to carry the day. This time, the college has decided that a supermajority of 60% is needed for either side to win. Since neither the pro nor anti doctors are expected to reach this threshold, the organisation looks likely to default to a neutral stance. https://econ.st/2SrSzWm

Specialist Publications

Lifestyle medicine interventions in patients with advanced disease receiving palliative or hospice care

AMERICAN JOURNAL OF LIFESTYLE MEDICINE | Online – 15 February 2019 – Lifestyle medicine interventions have the potential to improve symptom management, daily function, and quality of life (QoL) in patients with advanced or terminal disease receiving palliative or hospice care. The goal of this review is to summarize the current state of the literature on this subject. Four main categories of lifestyle interventions feature prominently in the palliative care literature: exercise, nutrition, stress management, and substance use. High-quality studies in this vulnerable population are relatively sparse. Some interventions show promise. However, most show mixed results or inadequate evidence. For some interventions, risks in this generally frail population outweigh the benefits. Clinical decision making involves balancing research findings, including the risks and benefits of interventions, with a clear understanding of patients' prognosis, goals of care, and current physical, emotional, and spiritual state. Achieving optimum QoL, safety, and ethical care are emphasized. There is potential for considerable benefits; however, more research is needed. **Abstract:** http://bit.ly/2S7Kb9z

Publishing Matters

'Questioning the efficacy of predatory journals' blacklists' (p.18), in *BJPsych*

'Predatory journals: Authors and readers beware' (p.18), in *Canadian Family Physician*

'Evidence and opportunities for palliative care across diverse populations and care settings' (p.18), in *Journal of Pain & Symptom Management.*

'University of Toronto checklist to spot deceptive publishers becomes national resource' (p.19), in *University of Toronto News.*

Breaking silence: A survey of barriers to goals-of-care discussions from the perspective of oncology practitioners

BMC CANCER | Online – 8 February 2019 – Oncology clinicians perceive patient and family factors as the most important barriers to goals-of-care (GoC) discussions. This insight forms an important platform for future interventions. The findings of this study highlight the potential for high levels of anxiety or even denial faced by patients with advanced cancer. This underscores the need for oncology clinicians to be equipped with strong communication skills to help patients and their families to navigate GoC decisions. Making time for these crucial conversations and planning to have them throughout the course of illness is imperative. GoC discussions should be initiated by physicians and nurses who have received focused training in this regard... **Full text:** http://bit.ly/2UQIxLd

Cultural safety strategies for rural Indigenous palliative care: A scoping review

BMC PALLIATIVE CARE | Online – 14 February 2019 – The authors review of peer-reviewed and grey literature about Indigenous palliative care (PC) in rural and small-town settings in Canada, the U.S., New Zealand, and Australia revealed various strategies to improve the relevance and cultural appropriateness of PC for Indigenous clients. They outlined two types of recommendations – those that aligned with a culturally competent framework, and those that were more oriented towards cultural safety. Although the authors' search was focused on rural Indigenous populations, because of the lack of specificity to rural contexts of recommended activities these initiatives are likely applicable to other contexts. Culturally competent strategies focused on building opportunities or creating space to accommodate the unique values and traditions of Indigenous patients, families and communities. One strength of these types of approaches is they coach non-Indigenous clinicians to challenge assumptions of universality and consider how cultural difference and historical context may shape care preferences of their Indigenous clients. One key risk of culturally competent approaches is that without an awareness of provider privilege and power, institutional norms, or historical oppression, they may enforce simplistic stereotypes, essentialization, and stigma of Indigenous peoples. Given the diverse spiritual and cultural practice between Indigenous communities, cultural competence will only be a value added if it is applied with a great deal of humility and genuine curiosity for the individuality and uniqueness of each client. Partnered approaches to care may enable clinicians to transition towards a culturally safe approach to PC because partnerships may prompt the individual to consider power at the interpersonal level. **Full text:** http://bit.ly/2EcF6ZO

Development and validation of a French questionnaire concerning patients' perspectives of the quality of palliative care: The QUALI-PALLI-Patient

BMC PALLIATIVE CARE | Online – 11 February 2019 – Quali-Palli-Pat appears to be a valid, reliable, and well-accepted French tool to explore the quality of care and the satisfaction of palliative care (PC) patients. Quali-Palli-Pat largely explores the communication between patients and health providers. This is an extremely important domain, especially when deciding to stop specific treatments, such as chemotherapy, and at the beginning of exclusive PC. *Teno et al* previously highlighted this domain and developed a specific tool focusing on information needs, especially at the time of diagnosis or making decisions concerning treatment.[1] In this study, this domain showed the lowest values, highlighting the necessity of further improvement, especially in PC units. A single item concerned spirituality ("I can talk to someone about philosophical or religious issues if I wish"), but with a rate of 27% of non-applicable (NA) responses, despite its harmless formulation, this item would have been deleted according to the authors' rules. However, it was retained by the working group because spirituality is an essential component of PC.[2,3] The NA response can be explained by the specificity of French secularism, which considers religious or spiritual domains as private; French patients cannot understand the relationship between care, quality of care, and spirituality.[4] **Full text:** http://bit.ly/2USOW8H

1. 'Cancer patient assessment and reports of excellence: Reliability and validity of advanced cancer patient perceptions of the quality of care,' *Journal of Clinical Oncology*, 2009;27(10):1621-1626. **Full text:** http://bit.ly/2thrBBI

Cont.

2. 'Culture and spirituality: Essential components of palliative care,' *Postgraduate Medical Journal*, published online 2 March 2016. Noted in the 7 March 2016 issue of Media Watch (#452, p.13). **Abstract:** http://bit.ly/2SIOTyN

3. 'Development and preliminary testing of the quality of spiritual care scale,' *Journal of Pain & Symptom Management*, 2014;47(4):793-800. **Full text:** http://bit.ly/2GABcf0

4. 'Pilot-testing the French version of a provisional European organisation for research and treatment of cancer (EORTC) measure of spiritual well-being for people receiving palliative care for cancer,' *European Journal of Cancer Care*, 2014:23(2):221-227. **Abstract:** http://bit.ly/2RU9rjr

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* – 14 February 2019 – **'Palliative care quality measures: An exploratory study.'** The Veneto Regional Health Authorities [in north-eastern Italy] collected a set of 37 quality indicators … covering the five dimensions: 1) Service integration; 2) Service structure; 3) Accessibility; 4) Professional processes; and, 5) Organisational processes. Their validity was assessed by a panel of 29 PC experts. Despite its limitations, this study brought to light some statistically significant findings that are worth investigating in larger samples. **Abstract:** http://bit.ly/2S4HNjH

Primary palliative care research [in the U.K.]: Opportunities and challenges

BMJ SUPPORTIVE & PALLIATIVE CARE – 12 February 2019 – Primary care has a central role in palliative and end-of-life care: 45.6% of deaths in England & Wales occur under the care of primary care teams at home or in care homes. The Community Care Pathways at the End of Life (CAPE) study investigated primary care provided for patients in the final 6 months of life. This paper highlights the opportunities and challenges associated with primary palliative care research in the U.K., describing the methodological, ethical, logistical and gatekeeping challenges encountered in the CAPE study and how these were addressed. Considerable difficulties were encountered with ethical permissions, with general practitioner, district nurse and bereaved carer recruitment and both quantitative and qualitative data collection. These were overcome with flexibility of approach, perseverance of the research team and strong user group support. This enabled completion of the study which generated a unique primary palliative care data set. **Full text:** http://bit.ly/2WVc3S1

Do family health clinics provide primary-level palliative care in Ontario and the eastern regions of Quebec?

CANADIAN FAMILY PHYSICIAN, 2019;65(2):118-124. A group of clinics are providing full palliative care (PC) services to their own patients with PC needs, including "on-call" services and home visits, and these serve as role models. In Ontario in particular, substantial gaps still exist with respect to clinics providing their own after-hours coverage and home visits; many rely on other services to provide that care. In Quebec, lack of access to PC specialist teams appears to be a key challenge in the areas included in this survey. This survey could help policy makers and funders of health care services ensure that appropriate conditions are put in place for optimal PC provision in these clinics, such as coordinating access to on-call coverage and support from PC specialist teams, as well as providing education to all physicians and adequate remuneration. **Full text:** http://bit.ly/2tmVq3Y

Barriers to staff involvement in end-of-life decision-making for long-term care residents with dementia

CANADIAN JOURNAL ON AGING | Online – 11 February 2019 – Although providing direct care to residents with dementia, long-term care (LTC) home staff of registered nurses', registered practical nurses', and personal support workers' involvement in end-of-life (EoL) decision-making is rarely acknowledged. The purpose of this study was to examine barriers and facilitators to LTC home staff involvement in EoL decision-making for people with advanced dementia. The authors report on the barriers to staff involve-

Cont.

ment in decision-making. Using an interpretive descriptive design, four major barriers to staff involvement in decision-making were identified: 1) The predominance of a biomedical model of care; 2) A varied understanding of a palliative approach; 3) Challenging relationships with families; and, 4) A discomfort with discussing death. Findings suggest that the predominant biomedical model in LTC homes, while important, must be imbued with a philosophy that emphasizes relationships among residents with dementia, family and staff. **Abstract (w. list of references):** http://bit.ly/2WVwxKl

Noted in Media Watch 11 February 2019 (#601, p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 8 February 2019 – **'Advance care plans in dementia: User-centred design.'** There are many challenges providing palliative and end-of-life (EoL) care to this group of people, some of which may be reduced through advance care planning (ACP) to support people with dementia to have a greater influence on their care at the EoL. The objective of this project was to involve people with dementia and their family carers in co-design of ACP guide and template... **Abstract:** http://bit.ly/2So5Sav

N.B. Selected articles on advance care planning, advance directives and end-of-life decision-making for people living with Alzheimer's disease and other forms of dementia noted in 7 January 2019 issue of Media Watch (#596, pp.9-10).

Paramedics providing palliative care at home: A mixed-methods exploration of patient and family satisfaction and paramedic comfort and confidence

CANADIAN JOURNAL OF EMERGENCY MEDICINE | Online – 11 February 2019 – A palliative home care program for paramedics was launched in two [Canadian] provinces, preceded by the extension of a clinical practice guide, the updating of a database and the development of special training for paramedics. The level of patient and family satisfaction as well as the level of comfort and confidence of paramedics were evaluated. After the implementation of this multi-faceted program, paramedics viewed palliative care as an important and rewarding gesture. The program resulted in a high degree of satisfaction for both patients and families, and the ease of registration provided peace of mind. Finally, after a meeting, families particularly emphasized the professionalism and compassion of paramedics. **Abstract (w. list of references):** http://bit.ly/2TJhMYV

Noted in Media Watch 4 February 2019 (#600, p.1):

- CANADA | *The National Post* – 29 January 2019 – **'Palliative paramedic program to train thousands in end-of-life care.'** Health authorities across the country are getting funds to train thousands of paramedics to deliver palliative care. The Canadian Partnership Against Cancer and the Canadian Foundation for Healthcare Improvement say they are jointly providing up to $5.5 million over the next four years for the plan in six provinces. The program is based on existing models in Nova Scotia, Prince Edward Island and Alberta. http://bit.ly/2sUKVos

Healthcare utilization and costs for patients with end-stage liver disease [in Ontario, Canada] are significantly higher at the end of life compared to those of other decedents

CLINICAL GASTROENTEROLOGY & HEPATOLOGY | Online – 8 February 2019 – In a population-based study in Canada, the authors found that patients with end-stage liver disease (ESLD) incur significantly higher end-of-life care (EoLC) costs than decedents without ESLD, predominantly due to increased time in hospital during the final 90 days of life. The median age at death [of the patient population studied] was significantly lower for ESLD decedents … than for individuals without ESLD... The median cost in the last year of life was significantly greater for patients with ESLD ($51,235 vs $44,456 without ESLD). Median ESLD EoLC costs also significantly exceeded those associated with 4 of the 5 most resource-intensive chronic conditions ($69,040 for ESLD vs $59,088 for non-ESLD). Cost differences were most pronounced in the final 90 days of life. During this period, patients with ESLD spent 4.7 more days in the hospital … than patients without ESLD, had significantly higher odds of dying in an institutional setting …, and incurred an additional $4,201 in costs… **Abstract:** http://bit.ly/2GISRku

Cont.

Related

- *LIVER TRANSPLANTATION* | Online – 13 February 2019 – **'Current knowledge, barriers to implementation, and future directions in palliative care for end stage liver disease.'** End stage liver disease (ESLD) is increasing in incidence, resulting in a greater burden on the healthcare system, which is estimated to cost over $2 billion each year. Unfortunately, many of these expenditures fail to meaningfully improve or prolong life for patients. In addition to these costs, patients with ESLD suffer a high burden of symptoms and invasive procedures, even when death may be imminent. **Abstract:** http://bit.ly/2UWqinN

Noted In Media Watch 26 November 2018 (#591, p.15):

- *THE LANCET GASTROENTEROLOGY & HEPATOLOGY* | Online – 21 November 2018 – **'Unmet needs in end-of-life care for chronic liver disease.'** Despite improvements in other chronic diseases, liver disease mortality increased by 400% in the U.K. between 1970 and 2010, resulting in rising pressures on acute hospital services, and an increasing need for end-of-life care. **Abstract (w. list of references):** http://bit.ly/2tpQjQo

Community-based specialist palliative care teams and health system costs at end of life: A retrospective matched cohort study [in Ontario, Canada]

CMAJ OPEN | Online – 12 February – Access to community-based specialist palliative care (SPC) teams has been shown to improve patients' quality of life; however, the impact on health system expenditures is unclear. The findings of this study suggest that access to community-based SPC teams, in addition to usual care (which was primarily end-of-life home care services), helps to reduce end-of-life hospital costs. These findings were consistent even though the teams differed in geographic area served, team size and team organization. Generally, teams seemed to keep patients in the home and avoid or reduce hospital admissions. Because the teams aim to expertly manage, constantly monitor and rapidly respond to complex symptoms and changes in the patient's condition in the home 24/7, they can help patients to stay at home where they might otherwise go to hospital. The cost of home care service – including the cost of delivering community-based SPC teams – was a fraction of the cost of a hospital bed, which typically ranges from $1,000 to $2,000 per day for non-critical care; this can lead to overall health system savings. Furthermore, support and education from the SPC teams may prompt patients and families to choose comfort care measures rather than aggressive treatments in hospital. Nonetheless, 4 of the 11 community-based SPC teams … did not individually show significant cost savings. This may be due to a few factors: they tended to be very small teams, serving no more than 40-100 decedents per year in large rural or suburban geographic areas. As well, two of the teams only had a half-fulltime equivalent palliative care physician. **Full text:** http://bit.ly/2N5P5Tq

Palliative cancer care in the outpatient setting: Which model works best?

CURRENT TREATMENT OPTIONS IN ONCOLOGY | Online – 11 February 2019 – Multiple randomized controlled trials have underscored the importance of timely referral to palliative care (PC) for patients with advanced cancer. Outpatient PC can facilitate timely referral and is increasingly available in many cancer centers. The key question is which model of outpatient PC is optimal. There are currently many variations for how PC is delivered in the outpatient setting, including: 1) Interdisciplinary specialist PC in stand-alone clinics; 2) Physician-only specialist PC in stand-alone clinics; 3) Nurse-led specialist PC in stand-alone clinics; 4) Nurse-led specialist PC telephone-based interventions; 5) Embedded specialist PC with variable team makeup; and, 6) Advanced practice providers-based enhanced primary PC. It is important to make a clear distinction among these delivery models of outpatient PC because they have different structures, processes, and outcomes, along with unique strengths and limitations. In this review article, the authors provide a critical appraisal of the literature on studies investigating these models. At this time, interdisciplinary specialist PC in stand-alone clinics remains the gold standard for ambulatory PC because this approach has the greatest impact on multiple patient and caregiver outcomes. Although the other models may require fewer resources, they may not be able to provide the same level of comprehensive PC as an interdisciplinary team. **Opinion statement (w. list of references):** http://bit.ly/2USApKb

Four in five GPs [in the U.K.] struggle to find time to care for dying patients, survey shows

GP | Online – 14 February 2019 – The Royal College of General Practitioners (RCGP) has published quality improvement standards for end-of-life care (EoLC) in general practice after it was revealed that more than four in five GPs want more time to support terminally ill or dying patients. Despite the vast majority of GPs agreeing that EoLC is an "important" (92%) and "rewarding" (87%) part of general practice, 85% say that heavy workloads leave them unable to deliver it to the standard they would like. It was also found that 62% of more than 1,000 GP respondents felt there was not enough community support available to cater to the emotional needs of the family and friends of terminally ill patients. The survey … coincided with the launch of quality improvement standards designed by the RCGP and terminal illness charity Marie Curie. The standards are designed to support GPs and their teams in "delivering care to patients living with an advanced, serious or terminal illness and their loved ones." **Full text:** http://bit.ly/2SCJcDI

Daffodils set the standard for end-of-life care

ROYAL COLLEGE OF GENERAL PRACTITIONERS | Online – 13 February 2019 – GP surgeries will now be able to display a "daffodil mark" as a sign of commitment to improving end-of-life care, as part of a new partnership between the College and the charity Marie Curie. The mark, synonymous with the charity, is based on a new set of criteria called the Daffodil Standards – a set of eight quality improvement statements designed to support primary care teams in delivering care to patients living with an advanced, serious illness or at the end of their lives, and their loved ones. By adopting the Standards, GP practices commit to making improvements in at least three of eight core aspects of care each year, with the aim of having reviewed all of them after three years. **Download/view at:** http://bit.ly/2SOEH8c

N.B. 'Palliative and End of Life Care Toolkit,' Royal College of General Practitioners. **Download/view at:** http://bit.ly/2GI2LTJ

Addressing the bereavement needs of children in school: An evaluation of bereavement training for school communities

IMPROVING SCHOOLS | Online – 2 February 2019 – The role of schools in both educating children about loss and change and supporting bereavement experiences is emphasised, yet school staff report low confidence in being able to support children when someone dies. This article reports on an evaluation of bereavement training that was offered to eight schools in Scotland and aimed to assist school communities to develop knowledge and confidence in engaging and supporting bereaved children. Pre and post questionnaires were used to measure the confidence, beliefs and values of 282 school staff that attended the training. Two focus groups were held for 6-18 months following the training to gain an understanding of the longer-term impact. Findings of this study suggest that participants viewed bereavement support as part of their role and that a short and targeted bereavement-training programme can contribute to raising the awareness and confidence of school staff to respond to the needs of bereaved children. **Abstract:** http://bit.ly/2GAevaN

Canadian Virtual Hospice | Portail canadien en soins palliatifs

Supporting Grieving or Bereaved Children
http://bit.ly/2sQ2bLy

IPCRC.NET International Palliative Care Resource Center

Back Issues of Media Watch
http://bit.ly/2ThijkC

A practical approach to assessing and mitigating loneliness and isolation in older adults

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 14 February 2019 – Despite the adverse impacts of loneliness and social isolation on quality of life, and their strong association with health outcomes, the evaluation of loneliness and isolation have not been integrated into medical care. The risks for loneliness may be of particular concern to persons with serious illness as patients and caregivers cope with the experience of loss, loss of independence, and increasing care needs. To date, there has been no uniform way of evaluating and documenting loneliness and social isolation as a part of a review of a patient's social determinants of health. This article provides a framework for healthcare systems, providers, and community members working with older adults to 1) understand loneliness, isolation, and its counterpart social connection; 2) describe the different ways loneliness affects health; and, 3) create a framework for asking about and documenting these experiences. Finally, because the lack of studies assessing whether targeting loneliness can improve health outcomes is a major gap, we provide guidance on the future of interventions. **Abstract:** http://bit.ly/2S4KwJX

> **N.B.** Additional articles on the potential detrimental effect on health of loneliness and isolation noted in 12 November 2018 issue of Media Watch (#589, p.10).

It is never lawful or ethical to withdraw life-sustaining treatment from patients with prolonged disorders of consciousness

JOURNAL OF MEDICAL ETHICS | Online – 14 February 2019 – In English law there is a strong (though rebuttable) presumption that life should be maintained. This article contends that this presumption means that it is always unlawful to withdraw life-sustaining treatment from patients in permanent vegetative state (PVS) and minimally conscious state (MCS), and that the reasons for this being the correct legal analysis mean also that such withdrawal will always be ethically unacceptable. There are two reasons for this conclusion. First, the medical uncertainties inherent in the definition and diagnosis of PVS/MCS are such that, as a matter of medical fact, it can never be established, with the degree of certainty necessary to rebut the presumption, that it is not in the patient's best interest to remain alive. And second (and more controversially and repercussively), that even if permanent unconsciousness can be unequivocally demonstrated, the presumption is not rebutted. This is because there is plainly more to human existence than consciousness (or consciousness the markers of which can ever be demonstrated by medical investigations). It can never be said that the identity of the patient whose best interests are at stake evaporates (so eliminating the legal or ethical subject) when that person ceases to be conscious. Nor can it be said that the best interests of an unconscious person do not mandate continued biological existence. We simply cannot know. That uncertainty is legally conclusive, and (subject to resource allocation questions and views about the relevance of family wishes and the previously expressed wishes of the patient) should be ethically conclusive. **Abstract:** http://bit.ly/2GqJGG9

Interdisciplinary teams and home-based medical care [in the U.S.]: Secondary analysis of a national survey

JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE | Online – 6 February 2019 – Sixty percent of [of the 246 home-based medical care (HBMC)] practices included in this study held routinely scheduled IDT meetings. Most practices that used interdisciplinary teams (IDTs) reported meeting weekly (42.2%) or monthly (26.5%). The most common practice team configurations included billing providers without teams (45.9%), billing providers with both a care coordinator and nurse (23.7%), then practices with either a billing provider and nurse (14.9%) or a billing provider with a care coordinator (14.2%). Practices that conducted regular IDT meetings were more likely to be a group practice rather than solo practice, be owned or sponsored by a primary hospital or health system rather than an independent practice, be financially subsidized by a hospital or health system rather than be independently financed, be affiliated with an academic institution rather than not, and be a not-for-profit vs for-profit entity. There is substantial diversity in IDT integration in HBMC practices. Routine IDT care in HBMC will improve care quality but will require clear standards and accountability for it to be fully integrated into HBMC practice. **Abstract (inc. link to references):** http://bit.ly/2SFAwLD

End-of-life care in the England

Has the [U.K.'s] National Health Service Long Term Plan forgotten we are all going to die?

THE LANCET | Online – 2 February 2019 – 'NHS bosses in England say a new 10-year plan could save up to 500,000 lives,' reported the BBC when the NHS Long Term Plan was launched in January 2019.[1,2] The plan presents a new service model for the 21st century and makes the case for improvements in prevention, treatment, outcomes, care quality, and reducing health inequalities among other priorities. But you have to search hard to find any mention of end-of-life (EoL) care. Indeed, it's virtually hidden: care at the EoL appears in one short paragraph in a section headed with the upbeat "People will get more control over their own health and more personalised care when they need it." And the first benefit of improving and personalising EoL care is "a reduction in avoidable emergency admissions," clarifying that dying is inconvenient for the efficiency of hospitals. **Abstract (w. list of references):** http://bit.ly/2SAmR9L

1. 'NHS long-term plan: Focus on prevention "could save 500,000 lives,"' BBC News, 7 January 2019. https://bbc.in/2BJZTm7

2. 'NHS Long Term Plan,' National Health Service, January 2019. **Download/view at:** http://bit.ly/2tljjsT

Competing professional knowledge claims about mental capacity in the [English] Court of Protection

MEDICAL LAW REVIEW | Online – 11 February 2019 – This article analyses the role of evidence in resolving Court of Protection proceedings, drawing on qualitative data obtained from observations of the Court of Protection, a review of Court of Protection case files and interviews with social workers. It is argued that there is a hierarchy of professional evidence in mental capacity law. Psychiatric evidence is at the top of this hierarchy, whereas social work evidence is viewed as a less persuasive form of knowledge about mental capacity. The article argues that this is because mental capacity law views psychiatric evidence as a form of objective and technical expertise about capacity, whereas social work evidence is viewed as a form of subjective, experiential knowledge. In challenging this hierarchy, it is instead argued that mental capacity law should place greater weight on experiential knowledge emanating from a relationship with the subject of the proceedings, rather than elevating the status of psychiatric evidence about mental capacity. **Abstract:** http://bit.ly/2WUlBwu

Dying at home: The burden of medication management

MEDSCAPE | Online – 13 February 2019 – The management of medications in patients with late-stage disease is becoming a major area of concern. The aging population of patients and family caregivers and a shift to care in the home, even for the terminally ill, are critical factors underpinning this concern. The management and administration of medications to seriously ill patients for pain, dyspnea, constipation, and many other physical and psychological symptoms (including anxiety, agitation, and delirium) typically fall on the shoulders of nonprofessional family caregivers. But little is known about how these informal caregivers cope with the demands of the complex medication regimens required to provide comfort and symptom control for patients approaching death. A recent literature review explored the experiences and perspectives of family caregivers in managing medications for a family member being cared for and dying at home.[1] The authors reviewed 15 studies in this area and synthesized the findings into five key themes that provide a framework to improve support for these caregivers: These concepts provide important perspectives on caregiver fears, such as overmedicating the patient, and challenges in understanding instructions, particularly with multiple medications. **Full text:** https://wb.md/2X43MeD

1. 'Managing medicines for patients dying at home: A review of family caregivers' experiences.,' *Journal of Pain & Symptom* Management, published online 11 September 2018. [Noted in 17 September 2018 issue of Media Watch (#581, p.12)] **Full text:** http://bit.ly/2tli8t8

Cont.

Noted in Media Watch 29 October 2018 (#587, p.7):

- *THE GERONTOLOGIST* | Online – 24 October 2018 – **‘Stressors and resources related to medication management: Associations with spousal caregivers’ role overload.’** Managing medications can be stressful for spousal caregivers, but little is known about particular aspects of medication management that are most consequential for caregiving outcomes. The authors examined care stressors and resources related to medication management, their associations with role overload among spousal caregivers, and whether these links vary by care recipients’ number of chronic health conditions and dementia status. **Abstract:** http://bit.ly/2IfAXIA

  N.B. additional articles on management of medications in the home palliative care setting noted in this issue of Media Watch.

Palliative care specialists in hospice and hospital/community teams [in London, England] predominantly use low doses of sedative medication at the end of life for patient comfort rather than sedation: Findings from focus groups and patient records for I-CAN-CARE

PALLIATIVE MEDICINE | Online – 12 February 2019 – Little research has explored the detail of practice when using sedative medications at the end of life (EoL). One work package of the I-CAN-CARE research programme investigates this in U.K. palliative care. The authors’ findings, corroborated by patient record data, demonstrate that, when using sedatives at the EoL, current practice in the London settings studied is cautious and proportionate, as per European Association of Palliative Care (EAPC) recommendations.[1] Clinicians first consider using sedatives if patients are agitated and/or experiencing considerable anxiety or distress, and, if used, begin with low doses if possible, aiming primarily to increase patient comfort. Sedation, if it occurs, is a by-product, so this approach is best described as proportionate sedation. The only variation the authors found from EAPC recommendations for drugs, dosages and monitoring was that clinicians did not objectively monitor sedative effects, even when using moderate to high doses of sedatives. **Full text:** http://bit.ly/2UT5P35

[1] ‘European Association for Palliative Care recommended framework for the use of sedation in palliative care,’ *Palliative Medicine*, published online 26 October 2009. Noted in 2 November 2009 issue of Media Watch (#121, p.8). **Abstract:** http://bit.ly/2E7KeOV

Related

- *JOURNAL OF PALLIATIVE CARE* | Online – 13 February 2019 – **‘The use of palliative sedation to treat existential suffering: A scoping review on practices, ethical considerations, and guidelines.’** Out of 427, 71 full text articles were obtained, 20 of which were included. Out of these articles, four themes were identified as key findings: 1) Ethical considerations; 2) The role of the health care provider (looking specifically at the impact on nurses); 3) The need for multidisciplinary care teams; and, 4) Existential suffering’s connection to religiosity and spirituality. **Abstract:** http://bit.ly/2UUHZ7d

Noted in Media Watch 4 February 2019 (#600, p.13):

MÉDECINE PALLIATIVE | Online – 30 January 2019 – **‘Palliative sedation and terminal sedation.’** End-of-life situations where pharmacological sedation can be considered are first of all important relational issues between patient, relatives and caregivers. The respect of these issues shapes practice. Two forms of sedation can therefore be distinguished. Palliative sedation is part of the relational anthropology of palliative care. Conversely, terminal sedation is part of the technical perspective and the conceptual framework of euthanasia. **Abstract:** http://bit.ly/2WnZK06

N.B. French language article. Additional articles on palliative and terminal sedation noted in 14 January issue of Media Watch (597, pp.6-7).

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.20.

Appointment utilization as a trigger for palliative care introduction: A retrospective cohort study

PALLIATIVE MEDICINE | Online – 12 February 2019 – Chronic kidney disease palliative care (PC) guidelines would benefit from more diverse and objectively defined health status measures. 45,368 [U.S.] Veterans, with chronic kidney disease Stage 3, 4, or 5, were monitored for up to 6 years and categorized into three groups, based on whether they died, started dialysis, or avoided both outcomes. Patient's appointment utilization was a significant predictor for both outcomes. It separated individuals into low, medium, and high appointment utilizers. Among the low appointment utilizers, the risk of death did not change significantly, while the risk of dialysis increased. Medium appointment utilizers had a stable risk of death and a decreasing risk of dialysis. Significant appointment utilization (above 31 visits during the baseline year) helped high-risk patients avoid both … death and dialysis. The authors' model could justify the creation of a novel PC introduction trigger, as patients with medium demand for care may benefit from additional PC evaluation. The trigger could facilitate the uniformization of conservative treatment preparations. It could prompt messages to a managing physician when a patient crosses the threshold between low and medium appointment utilization. It may also aid in system-level policy development. Furthermore, the results of this study highlight the benefit of significant appointment utilization among high-risk patients. **Abstract:** http://bit.ly/2Duz2KF

Metasynthesis: Dying adults' transition process from cure-focused to comfort-focused care

JOURNAL OF ADVANCE NURSING | Online – 7 February 2019 – The authors analysed 56 unique reports from 50 primary studies. Patients and families emphasized the importance of receiving understandable information, emotional support, respect for personhood and control. The critical juncture of "realizing terminality" preceded a transition to comfort-focused care. Subsequently, a shift in goals-of-care emphasizing comfort and quality of life could occur. Continued provision of information, effective support, respect and control promoted "reframing perceptions" and capacity to embrace a changed identity. Reframing allowed patient and family to find meaning and value in this last phase of life and to embrace the opportunity to prepare for death, nurture relationships and focus on quality of living. **Abstract:** http://bit.ly/2E7KflY

Noted in Media Watch 21 January 2019 (#598, p.7):

- *CLINICAL MEDICINE*, 2019;19(1):26-29. **'Unique palliative care needs of patients with advanced chronic kidney disease: The scope of the problem and several solutions.'** Patients with advanced chronic kidney disease (CKD), including end-stage renal disease (ESRD), have a life-threatening illness complicated by high morbidity and mortality and, therefore, should be suitable candidates for early intervention by palliative care (PC) specialists. The authors outline the scope of the problem of unmet PC needs for patients with advanced CKD and ESRD, barriers to improving PC for patients with renal failure, and possible future directions for palliative nephrology. **Abstract:** http://bit.ly/2UZflwe

N.B. Selected articles on palliative and end-of-life care for people living with chronic kidney disease noted in 13 August 2018 issue of Media Watch (#576, p.15).

Long-term prevalence and predictors of prolonged grief disorder amongst bereaved cancer caregivers: A cohort study

PALLIATIVE & SUPPORTIVE CARE | Online – 11 February 2019 – The short-term impact of prolonged grief disorder (PGD) following bereavement is well documented. The longer term sequelae of PGD however are poorly understood, possibly unrecognized, and may be incorrectly attributed to other mental health disorders and hence undertreated. A cohort of primary family caregivers of patients admitted to one of three palliative care (PC) services in Melbourne, Australia, participated in this study. For almost 20% of caregivers, the symptoms of PGD appear to persist at least three years post bereavement. These findings support the importance of screening caregivers upon the patient's admission to PC and at six months after bereavement to ascertain their current mental health. Ideally, caregivers at risk of developing PGD can be identified and treated before PGD becomes entrenched. **Abstract (w. list of references):** http://bit.ly/2EdeWGu

Distress and self-care among chaplains working in palliative care

PALLIATIVE & SUPPORTIVE CARE | Online – 11 February 2019 – The prevalence of burnout and distress among palliative care (PC) professionals has received much attention since research suggests it negatively impacts the quality of care. Although limited, research suggests low levels of burnout or distress among healthcare chaplains; however, there has been no research among chaplains working in specific clinical contexts, including PC. More than 60% of chaplains working in PC [i.e., survey respondents] reported feeling worn out in the past three months because of their work as a helper... Chaplains working in PC appear moderately distressed, possibly more so than chaplains working in other clinical areas. These chaplains also use debriefing, with non-chaplain palliative colleagues, to process clinical experiences. Further research is needed about the role of religious or spiritual beliefs and practices in protecting against stress associated with care for people at the end of life. **Abstract (w. list of references):** http://bit.ly/2E3Vfk4

N.B. Additional articles on the role of chaplains in palliative care noted in 22 October 2018 issue of Media Watch (#586, pp.5-6).

Minority patient preferences, barriers, and facilitators for shared decision-making with health care providers in the U.S.: A systematic review

PATIENT EDUCATION & COUNSELING | Online – 10 February 2019 – This systematic review of contemporary literature sought to better understand racial and ethnic minority patients' shared decision-making (SDM) preferences, challenges and facilitators. From over 5,000 publications identified through the search strategy, 18 met eligibility criteria… Studies focused on SDM in developing treatment plans, and were conducted in primary care or hospital/health system settings. Patients' decision preferences ranged from physician-driven altogether or initially, to patient-driven style. A comprehensive list of SDM facilitators and barriers was developed. Despite strong policy and research SDM support to increase patient communication and a growing published literature, results suggest lack of representation of minority populations in contemporary literature. Provider training may be needed to facilitate patient-provider transition from a passive toward a more active SDM engagement over time while confidence, trust and rapport is established. **Abstract:** http://bit.ly/2N1RnTz

Withholding or withdrawing invasive interventions may not accelerate time to death among dying ICU patients

PLOS ONE | Online – 14 February 2019 – Despite the expectation that patients would die sooner if invasive interventions were withheld or discontinued, the authors of this study found no such association. Although it is likely some individuals died more quickly because endotracheal ventilation and/or vasopressors and inotropes were not administered, for other patients, such invasive interventions may hasten their deaths. Therefore, the assumption that invasive intervention is always life sustaining in this context may be incorrect. For clinicians carrying on end-of-life discussions with patients and families regarding using, withholding or discontinuing invasive therapies, this study should provide useful information in terms of the likely impact of such decisions on remaining survival durations. **Full text:** http://bit.ly/2TQ782N

Developing educational modules to enhance care of aged and dying inmates: Set-up phase

PUBLIC HEALTH NURSING | Online – 7 February 2019 – Public health nurses have an opportunity to support efforts in educating corrections staff to enhance health care for older and dying inmates. Such endeavors can promote social justice through inmates receiving evidence-based care that parallels that received by the community at large. "Set-up" is the first of four phases in the Institute for Healthcare Improvement's Framework for Going to Full Scale. The design approach was threefold and included an environmental scan, a modified Delphi survey, and a usability study. An expert advisory board was consulted throughout the Set-up Phase. Participants for the Delphi Survey had expertise in geriatrics and

Cont.

corrections health care. Usability testing was conducted at two State Correctional Institutions [in the U.S.]. The Delphi Survey consisted of three Qualtrics surveys. Usability testing examined navigability; detected problems; observed time spent solving problems; identified problem severity; and, developed recovery strategies. The Set-up phase has been instrumental in exposing the available infrastructure for dissemination of an educational product within corrections and may be a first step in addressing public health concerns on issues in aging. **Abstract:** http://bit.ly/2DteEJV

> **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 2019) can be downloaded/viewed at the Palliative Care Network website at: http://bit.ly/2RdegnL

Guidelines updated for pulmonary arterial hypertension in adults

RENAL & UROLOGY NEWS | Online – 14 February 2019 – In the latest evidence-based guideline from the American College of Chest Physicians … updated recommendations are provided for the management of adults with pulmonary arterial hypertension.[1] The authors developed two … ungraded consensus-based statements on palliative care (PC). The consensus-based statements suggest incorporating PC services for patient management... **Full text:** http://bit.ly/2E97RXg

1. 'Therapy for Pulmonary Arterial Hypertension in Adults 2018,' *Chest*, published online 17 January 2019. **Full text:** http://bit.ly/2DIXSXc

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *MEDSCAPE* | Online – 6 February 2019 – **'*Medscape* Psychiatrist Ethics Report 2018.'** *Medscape* surveyed more than 5,200 physicians [in the U.S.], including more than 330 psychiatrists, to find out how they feel about key issues they wrestle with today. More than half of psychiatrists approved of making physician-assisted legal in the U.S., essentially the same number as in the 2016 *Medscape* Ethics Report. https://wb.md/2GF5gGd

- *NATIONAL LAWYER'S GUILD REVIEW*, 2018;75(2):100-127. **'Measuring mercy: Protecting patient discretion in terminal care under the [U.S.] Fourteenth Amendment.'** In recent years, studies have shown that a substantial minority of terminal patients experience irremediable pain during the dying process and are incapable of receiving relief through modern medicine. In cases of irremediable pain, competent, terminally ill adults must be allowed to pursue medical improvement equally with non-terminal patients by seeking palliative care (PC), including palliation with both palliative and life-ending effects, such as physician-assisted suicide and euthanasia. To seek relief from pain is to exercise one of the most basic instincts of self-preservation. Additionally, the right of patients to determine the course of their own treatment is supported in case law by the Supreme Court's recognition of personal privacy. This article analyzes constitutional protections provided by the Fourteenth Amendment over terminal patients' right to seek PC and discusses the implications that these protections have concerning access to life-ending palliation in cases of irremediable pain. **Full text:** http://bit.ly/2tlGjYl

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 11 February 2019 – **'Factors affecting California college students' attitudes toward assisted dying.'** This study focuses on college students' experiences and beliefs, which affect attitudes toward assisted dying. Of 324 students, 35% wanted the option of assisted dying for a family member with a life-threatening illness. Results of multiple logistic regression indicate students who favored assisted dying were significantly influenced by having a family member die, experiencing hospitalization, thinking about end-of-life (EoL) issues, and being comfortable with palliative care. Belief in an afterlife and being a caregiver were negatively associated with assisted dying. Students need to receive training in EoL care issues, as increasingly professionals will face such requests. **Abstract:** http://bit.ly/2URNdAt

Publishing Matters

Questioning the efficacy of predatory journals' blacklists

BJPSYCH, 2019;25(2):120-121. The authors question whether blacklists are the best answer to the serious problem of predatory journals (PJs). In conjunction with the worrying recent rise in the number of PJs, a remarkable number of blacklists have been compiled for specific scientific fields. However, PJs are continuously changing names and publishers; they are set up to make easy money and buried shortly after. PJs have such a rapidly evolving nature that it is hard to keep track of them and keep blacklists up to date. The authors therefore propose a focus on "whitelists" and directories of virtuous journals rather than on blacklists of pseudo-journals. They suggest that a set of criteria be determined that journals have to meet to be qualify as legitimate. In addition, the scientific community should come up with strategies to close the established biomedical databases to PJs, thus preventing them from achieving global exposure. **Abstract (w. list of references):** http://bit.ly/2SQPw9P

> **N.B.** The authors of this article are commenting on 'Predatory journals and dubious publishers: How to avoid being their prey,' published online in *BJPsych*, 30 October 2018. **Abstract (w. list of references):** http://bit.ly/2IebkI3

Predatory journals: Authors and readers beware

CANADIAN FAMILY PHYSICIAN, 2019;65(2):92-94. Many academic family physicians, especially those involved in research, receive regular, frequent e-mails from medical journals requesting that they submit manuscripts or join editorial boards. Unfortunately, some authors who are not aware of predatory journals (PJs) succumb to the lure of submitting work to these dubious entities, only to have their payments wasted, their valuable research published in a non-credible journal, and their work held hostage. The current academic culture of "publish or perish" and the author fee model of article submission have contributed to the current situation. Hopefully the move of credible journals to waive author fees for those from low and middle-income countries will improve opportunities for these authors and reduce the number of PJs. In the meantime, we should all boycott PJs, both as readers and as authors. **Full text:** http://bit.ly/2SRV04a

> **N.B.** Commentary by the editor of *Canadian Family Physician*. **Full text:** http://bit.ly/2S78BQk

Evidence and opportunities for palliative care across diverse populations and care settings

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 11 February 2019 – Practices to optimize palliative care (PC) delivery and new opportunities in which to integrate PC vary across populations and care settings. Systematic reviews are an efficient and methodologically rigorous approach to summarize existing research to identify both evidence-based best-practices as well as new areas for future research and clinical practice. This is the introduction to a special series of articles in which members of the American Academy of Hospice & Palliative Medicine Research Committee report the results of circumscribed systematic reviews which in a specific population or care setting seek to: 1) Summarize existing evidence for optimal PC practices, or 2) Identify opportunities where better PC delivery could improve patient and/or family outcomes. **Abstract:** http://bit.ly/2tixfnl

Would these articles be of interest to a colleague?

Checklist to spot deceptive publishers becomes national resource

UNIVERSITY OF TORONTO NEWS | Online – 12 February 2019 – Some journals may have all the trappings of a reputable publication, but really just seek to turn a profit from unsuspecting academics. The University's Office of the Vice-President, Research & Innovation, worked with University's Libraries on a checklist that helps researchers spot these deceptive publishers before it's too late.[1] The resource, published under a creative commons license so it could be shared widely, was recently endorsed by Canada's Secretariat on Responsible Conduct of Research, which put it on its website and translated it into French. The Secretariat acts on behalf of Canada's three federal research funding agencies – the Canadian Institutes of Health Research, the Natural Sciences & Engineering Research Council and the Social Sciences & Humanities Research Council – and is dedicated to promoting good research practices. The University's checklist highlights more red flags that indicate a publication may be illegitimate: the time of submission to the publication is unexpectedly short; the journal name is easily confused with another better known journal in its field; it has an opaque peer-review process; and, it charges an article processing fee prior to acceptance. **Full text:** http://bit.ly/2DyrrLb

1. 'Deceptive Publishing,' University of Toronto Libraries. **Download/view at:** http://bit.ly/2N2oXcc

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[Scroll down to 'Barry Ashpole's Media Watch]

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