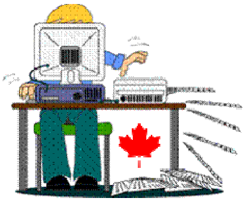
Media Watch...

*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.*

30 December 2019 Edition | Issue #646



Compiled & Annotated by Barry R. Ashpole

Asking about patients' hopes for their illness enables clinicians to quickly know some of their most important priorities. Giving patients the permission to be future-oriented and positive also supports them to cope in these challenging conversations.

'Chasing hope: When are requests for hospital transfer a place for palliative care integration?' (p.10), in *Journal of Hospital Medicine.*

Canada

Medical assistance in dying

Here's the deadline given to Delta Hospice

BRITISH COLUMBIA | *The Delta Optimist* (Ladner) – 24 December 2019 – The Fraser Health Authority (FHA) has given the Delta Hospice Society a deadline to agree to provide medically assisted deaths. The new board of the Society has been on a collision course with the health region after reversing a decision by the previous board to not allow medical assistance in dying (MAiD) at the Irene Thomas Hospice in Ladner. A spokesperson with the region yesterday told the *Optimist* that the FHA "reached out again to the Delta Hospice Society to share our expectations that they comply to permit MAiD by 3 February 2020." Health region representatives recently met with the leadership from the Delta Hospice to discuss the Society's compliance of their contract. The issue has been a heated and divisive one for the Society. The region's annual operating funding to the hospice could be pulled, provincial health minister Adrian Dix recently suggested. Currently, those at the hospice wanting the end-of-life procedure have to be transported to another facility. FHA approved its policy later that year that mandates hospices provide the procedure. http://bit.ly/2tM3AWZ

Specialist Publications

'The relationship of palliative care with assisted dying where assisted dying is lawful: A systematic scoping review of the literature' (p.10), in *Journal of Pain & Symptom Management.*

Cont. next page

Share this issue of Media Watch with a colleague

Noted in Media Watch 23 December 2019 (#645, p.1):

- BRITISH COLUMBIA | *The Delta Optimist* (Ladner) – 18 December 2019 – **'Canadian palliative society supporting Delta Hospice.'** The public and many healthcare providers have had a longstanding fear that hospice and palliative care (PC) hastens peoples' deaths, something that will be made worse if facilities are forced to provide medical assistance in dying (MAiD). That's what the Canadian Society of Palliative Care Physicians (CSPCP) is saying in a letter to the province's Health Minster Adrian Dix in support of the Delta Hospice Society... A CSPCP submission to a federal special joint committee on MAiD as well as a joint statement with the Canadian Hospice Palliative Care Association note hospice and PC and MAiD substantially differ in philosophy, intent and approach.[1,2] http://bit.ly/2r8VuH3

    1. 'Presentation to Special Joint Committee on Physician-Assisted Death,' Canadian Society of Palliative Care Physicians, July 2016. **Download/view at:** http://bit.ly/38TNbjj

    2. 'Joint Statement Regarding Palliative Care and Medical Assistance in Dying,' Canadian Hospice Palliative Care Association & Canadian Society of Palliative Care Physicians, December 2019. [Noted in 2 December 2019 issue of Media Watch (#642, p.1)]. **Download/view at:** http://bit.ly/33mmIad

U.S.A.

Patients don't care about provider religious ties, expect all needed care

REUTERS HEALTH | Online – 27 December 2019 – Nearly three quarters of Americans don't care about the religious affiliation of their hospital or healthcare network, but an equal number say they expect their healthcare preferences to take priority over the facility's religious doctrine, a new study finds.[1] The survey comes at a time when the number of Catholic-owned healthcare systems are on the rise, researchers note. And, perhaps unknown to many patients, physicians at those facilities are expected to follow the U.S. Conference of Catholic Bishops' "Ethical and Religious Directives for Catholic Health Care Services," which places limits on reproductive and end-of-life care methods. "We are seeing the composition of the U.S. healthcare system shifting," said the study's lead author, Dr. Maryam Guiahi, associate professor … [at] … the center for bioethics at the University of Colorado School of Medicine. "The number of Catholic-owned or affiliated healthcare facilities grew by 22% between 2001 and 2016," Guiahi said. "And this contrasts with the overall number of acute-care hospitals, which decreased by 6% and the number of other non-profit religious hospitals decreased by 38%. What this means is that increasingly more U.S patients will be seeking care in health facilities that may follow religious rules rather than evidence-based guidelines for care." Many patients may not realize that the religious affiliation of a healthcare system might impact the care they get... http://bit.ly/2Q8i6Br

Specialist Publications

'A review of the literature on native Hawaiian end-of-life care: Implications for research and practice' (p.7), in *Hawai'i Journal of Health & Social Welfare*.

'Hospice utilization in the U.S.: A prospective cohort study comparing cancer and non-cancer deaths' (p.9), in *Journal of the American Geriatric Society*.

'*Puente para cuidar* (bridge to caring): A palliative care patient navigator and counseling intervention to improve distress in Latino/as with advanced cancer' (p.12), in *Psycho-Oncology*.

1. 'Patient views on religious institutional healthcare,' *JAMA Network Open*, 2019;2(12):e1917008. **Full text:** http://bit.ly/2Qty5bT

Cont. next page

Noted in Media Watch (#613, p.2):

- CALIFORNIA | *Kaiser Health News* – 29 April 2019 – **'Will ties to a Catholic hospital system tie doctors' hands?'** As Catholic healthcare systems across the country expand, the University of California's flagship San Francisco (UCSF) hospital has become the latest arena for an emotional debate: Should the famously progressive medical center increase its treatment space by joining forces with a Catholic-run system that restricts care according to religious doctrine? At issue is a proposal that UCSF Medical Center affiliate with Dignity Health, a massive Catholic healthcare system that, like other Catholic chains, is bound by ethical and religious directives from the U.S. Conference of Catholic Bishops. http://bit.ly/2vtsmJ6

Noted in Media Watch 18 March 2019 (#606, p.7):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2019:321(11):1103-1104. **'Disclosure of religious identity and healthcare practices on Catholic hospital websites.'** Among U.S. Catholic hospitals, 21% did not explicitly disclose their Catholic identity on their websites, and only 28% specified how religious affiliation might influence patient care. A recent review demonstrated that patients are more likely to encounter reproductive restrictions at Catholic facilities compared with non-Catholic facilities; less is known about end-of-life care restrictions. If patients are unaware of the affiliation and encounter restrictions, refusal of or delay in care due to the need to go elsewhere can result in increased medical risk and contribute to wasted healthcare expenditures. **Full text:** http://bit.ly/2TAZX2e

N.B. Additional articles on Catholic perspectives on palliative and end-of-life care in the U.S. noted in 13 August 2018 issue of Media Watch (#576, p.2) and in 6 November 2017 issue of the weekly report (#537, pp.8-9).

Community members train doctors on palliative care

ALABAMA | *The Birmingham Times* – 26 December 2019 – Four palliative care (PC) doctors, two researchers and several community members gathered in this summer in Beaufort, South Carolina, to gain insight into the history and culture of two rural Southern communities, White and African American, and to understand the cultural values and preferences of each of these two ethnic groups in caring for patients with serious illness. Culture shapes how people make meaning out of illness, suffering and dying, and it influences their responses to diagnosis, prognosis and treatment preferences. Lack of respect for cultural differences may compromise care for seriously ill minority patients. However, culturally appropriate models of PC are not currently available. Until now, there was no such thing as culturally-based protocol for patients with serious illness or for end-of-life care, until this team of community members developed one for rural southern African Americans and another for Whites. http://bit.ly/2ETSWQj

Noted in Media Watch 24 July 2017 (#522, p.13):

- *NARRATIVE INQUIRY IN BIOETHICS*, 2017;7(1):36-40. **'A community-developed, culturally-based palliative care program for African American and White rural elders with a life-limiting illness: A program by the community for the community.'** African American and White caregivers in rural South Carolina who had been involved in the care of a loved one who had recently died, were asked what they found helpful or beneficial about the professional care and what they considered ineffective or inadequate. Gaining an understanding of their perspective was the first phase of this study. While this insight is important in and of itself, the more substantial purpose was to use this information to develop a culturally-based palliative care consult program... **Full text:** http://bit.ly/2ksejl7

Palliative care growth a 2020 priority

HOSPICE NEWS | Online – 23 December 2019 – The palliative care (PC) field can expect to see continued growth during 2020 despite the lack of a dedicated Medicare payment model, a continued need to raise public awareness, and ongoing staffing shortages.[1] About half of the community-based PC providers in the U.S. are hospices, according to recent research from the Center to Advance Palliative Care

Cont.

(CAPC).[2] CAPC developed an online survey to which 890 PC providers responded. Interest in PC has been rising in recent years among healthcare providers, payers and policymakers, driven by the benefits to patients, the need to engage patients earlier in the course of their illnesses, and the potential cost savings from reduced hospitalizations, readmissions and emergency department visits. Though CAPC reports that nearly 80% of consumers who received background information on PC would choose it for themselves or their loved ones, nearly 60% of patients who would benefit from those services do not receive them, studies have shown. One study published earlier this year found that 71% of adults in the U.S. are unaware that the service exists,[3] but some, including government resources and hospice providers themselves, have taken action to help address this. A number of states passed legislation designed to support PC during 2019. http://bit.ly/35UQtRI

1. 'Policy changes key to promoting sustainability and growth of the specialty palliative care workforce,' *Health Affairs*, 2019;38(6):910-918. [Noted in 10 June 2019 issue of Media Watch (#617, p.1)] **Full text:** http://bit.ly/2QMAU7N

2. 'Mapping community palliative care: A snapshot,' Center to Advance Palliative Care, December 2019. [Noted in 23 December issue of Media Watch (#645, p.3)] **Download/view at:** http://bit.ly/2tswrzB

3. 'Awareness of palliative care among a nationally representative sample of U.S. adults,' *Journal of Palliative Medicine*, published online 30 April 2019. [Noted in 6 May 2019 issue of Media Watch (#613, p.9)] **Abstract:** http://bit.ly/2UT2Ozi

Texas law highlights dilemma over care for patients with no hope of survival

TEXAS | *Kaiser Health News* – 23 December 2019 – While some physician groups prefer to talk about "potentially inappropriate" rather than futile care, the underlying quandary remains. What's the definition of "inappropriate," who can make that determination and how best to strike a balance between family members – if the patient is typically too ill or injured to weigh in – and the doctors and nurses who can become distressed providing care indefinitely without seeing any benefit? Texas is one of several states, including California and Virginia, that have enacted laws enabling doctors to withdraw life-sustaining treatment even if family members disagree, said Thaddeus Pope, who directs the Health Law Institute at Mitchell Hamline School of Law in St. Paul, Minnesota. These laws don't have a reporting requirement, so it's unknown how often the legal process is pursued, he said. Researchers have attempted to capture how often clinicians perceive medical care as futile. In one California study, doctors described the treatment they provided for 11% of their ICU patients as futile, and probably futile for an additional 8.6%.[1] Among the reasons they gave: the burdens of the treatment grossly outweighed the benefits or the patient was unable to live outside the ICU… http://bit.ly/2PQXM7a

1. 'The frequency and cost of treatment perceived to be futile in critical care,' *JAMA Internal Medicine*, 2013;173(20):1887-1894. **Full text:** http://bit.ly/34Uk24k

International

Fewer Scots to die while in hospital

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 22 December 2019 – Hospitals will no longer be the most common place to die in Scotland if trends continue, according to a leading charity. Research by Marie Curie, University of Edinburgh and Kings College London suggests two thirds of Scottish people will die at home, in a

Cont.

Specialist Publications

'Advance care planning in Norwegian nursing homes – limited awareness of the residents' preferences and values? A qualitative study' (p.5), in *BMC Geriatrics*.

'A comparison of policy analysis of palliative care for cancer in U.K., Malaysia, and South Africa' (p.8), in *International Journal of Cancer Management*.

care home or in a hospice by 2040 – despite less than half of deaths occurring in these places currently.[1] However, the terminal illness charity has warned that, without radical investment in community health and social care services, hospital deaths will rise again and could peak at 37,089 (57%) in 2040. In response to the research … charity Marie Curie is calling on the Scottish Government and Health & Social Care Partnerships to make care of people with a terminal illness a top priority. The research predicts there will be nearly 16% more deaths in Scotland in the next 20 years, taking the annual figure to 65,756. If current trends continue, the proportion of people who die at home will increase from 23% in 2016 to 29% by 2040. Similarly, deaths in Scottish care homes will increase from 19% to 29% over the same period. The proportion of people dying in hospital will fall. The findings contrast with a previous study reporting trends in England and Wales which found that care homes could overtake hospitals as the most common place for people to die by 2040.[2] http://bit.ly/2MlGWeJ

1. 'The impact of population ageing on end-of-life care in Scotland: Projections of place of death and recommendations for future service provision,' *BMC Palliative Care*, published online 19 December 2019. [Noted in 16 December 2019 issue of Media Watch (#644, p.8)] **Full text:** http://bit.ly/2qKez24

2. 'What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death,' *Palliative Medicine*, published online 10 October 2017. [Noted in 16 October 2017 issue of Media Watch (#534, p.16)] **Full text:** http://bit.ly/3714EF2

Specialist Publications

Advance care planning in Norwegian nursing homes – limited awareness of the residents' preferences and values? A qualitative study

BMC GERIATRICS | Online – 23 December 2019 – 52% of all deaths in Norway occur in nursing homes (NHs). This study adds insight into how advance care planning (ACP) is practiced in NHs, where the staff members have with little or no training and implementation support. Participants' focused on medical issues and achieving consensus on the resident's prognosis and treatment aims, and may be accompanied by limited awareness of the individual resident's needs, worries and hopes at the end of life (EoL). With blurry answers from residents and next of kin, this way of doing ACP hardly adds to the goal of increasing resident autonomy in EoL decisions. Interdisciplinary ACP may reduce the focus on medical issues and facilitate resident participation and supported decision-making. ACP is perceived as complex communication, and including residents with cognitive impairment makes these conversations even more challenging. Training and tailored guidelines may be useful to improve implementation and practice of ACP in NHs and to develop a broader understanding of the aims, content and possible outcome of ACP. **Full text:** http://bit.ly/2ZmDghW

Related

- *AUSTRALIAN JOURNAL OF PRIMARY HEALTH* | Online – 23 December 2019 – **'Prevalence, perceived barriers and socio-demographic correlates of advance care planning in a sample of outpatients.'** This study aimed to examine the prevalence and perceived barriers to uptake of advance care planning, including appointment of an enduring guardian (EG), and completion of an advance care directive (ACD) among Australian adults attending hospital outpatient clinics. The most common reason for non-completion of an ACD and not appointing an EG was: "didn't think I needed this." No socio-demographic characteristics were significantly associated with non-completion of ACDs. **Abstract (w. list of references):** http://bit.ly/2EM4OnG

Screening with the double surprise question to predict deterioration and death: An explorative study

BMC PALLIATIVE CARE | Online – 27 December 2019 – Early identification of palliative patients is challenging. The Surprise Question (SQ1: "Would I be surprised if this patient were to die within 12 months?") is widely used to identify palliative patients. However, its predictive value is low. Therefore, the authors added a second question (SQ2) to SQ1: "Would I be surprised if this patient is still alive after 12 months?" In this study, the DSQ demonstrated an innovative, easy and fast screening tool with the potential to predict individual death and palliative care (PC) needs of (older) patients in daily general practice as it divides the patient population into three groups with different life expectancy and care consumptions. Using the DSQ is not meant to predict survival, but to trigger GPs to think about the condition of the patient and to use this awareness while planning and providing PC. **Full text:** http://bit.ly/365JYLV

Palliative and end-of-life care in prisons: A mixed-methods rapid review of the literature from 2014-2018

BMJ OPEN | Online – 23 December 2019 – The key findings are: relationships are important to prisoners at the end of life (EoL), inmate hospice volunteers can build close bonds with the prisoners in their care and the prison environment and regime conflicts with best practices in palliative and EoL care. Directions for future research are also identified. Many of the key findings of this review reinforce points made in the Wion and Loeb review,[1] such as the value of inmate hospice volunteers and the physical barriers presented by the prison environment. Other findings which were relatively minor in the previous review have become major themes in the literature published since 2014, such as the importance of maintaining family relationships, and the potential grief burden of inmate hospice volunteers. Finally, this review adds the main finding that relationships both inside and outside of prison are of importance to prisoners at the EoL, and recommends that those involved in their care should support prisoners to maintain these relationships. **Full text:** http://bit.ly/2PTCRR2

Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, etc., noted in past issues of the weekly report can be downloaded from the Palliative Care Network website at: http://bit.ly/2RdegnL

Photo: Lori Waselchuk. Philadelphia, PA

1. 'End-of-life care behind bars: A systematic review,' *American Journal of Nursing*, published online 11 February 2016. [Noted in 15 February 2016 issue of Media Watch (#449, p.8)] **Abstract:** http://bit.ly/2ZmwfOe

Medical Cannabis Use in Palliative Care: Review of Clinical Effectiveness & Guidelines – An Update

CANADIAN AGENCY FOR DRUGS & TECHNOLOGIES IN HEALTH | Online – Accessed 24 December 2019 – Two evidence-based guidelines were included in this report. Their recommendations reflect the known high risk of adverse events of medical cannabis, coupled with uncertain benefit for palliative care (PC) patients and the availability of other treatment options. Canadian guidelines provide a strong recommendation against use of medical cannabis as first or second-line option for pain in PC. Both guidelines suggest that cannabis could be considered after other options and failed and with careful considera-

Cont.

tion of risks versus benefits. Both guidelines clearly described methods for evidence gathering, however the Australian guidelines did not adequately describe methods of development of recommendations. Neither provided an adequate description of patient involvement. Further research assessing effectiveness medical cannabis products available in Canada for improvement of symptoms and quality of life in the PC setting are needed to reduce uncertainty. **Download/view at:** http://bit.ly/2Qrq2wr

> **N.B.** Additional articles on medical cannabis in PC noted in 18 November 2019 issue of Media Watch (#640, pp.11-12).

Barriers in the decision making about and performance of continuous sedation until death in nursing homes

THE GERONTOLOGIST | Online – 18 December 2019 – While decision making about and performance of continuous sedation involve many challenges, they appear to be particularly pervasive in nursing homes. Ten focus groups were held with 71 healthcare professionals including 16 palliative care physicians, 42 general practitioners, and 13 nursing home staff. Perceived barriers concerned factors prior to and during sedation and were classified according to three types: 1) Personal barriers related to knowledge and skills including the lack of clarity on what continuous sedation should be used for (linguistic ambiguity) and when and how it should be used (practical ambiguity); 2) Relational barriers concerning communication and collaboration both between healthcare professionals and with family; 3) Organizational barriers related to the organization of care in nursing homes where, for example, there is no on-site physician, or where the recommended medication is not always available. There is a need for multicomponent initiatives that provide guidance in the context of the complexity of a resident's medical situation, the family, and the specific organization of care, which would have the potential to facilitate and improve the decision-making process and performance of continuous sedation in nursing homes. **Abstract:** http://bit.ly/2ZeIsEq

Related:

- *MEDICINA E MORALE*, 2019;68(4):397-410. **'Dying while intentionally deeply sedated: How can we ethically justify continuous deep palliative sedation?'** The authors argue that "imminence of death," generally understood as death anticipated within hours-to-days, is an important clinical criterion for determining the moral permissibility of the practice. In their discussion, they: 1) Explain why the doctrine of double effect, frequently referenced in these debates, does not necessarily apply; 2) Identify an alternative clinical and ethical justification for recourse to end-of-life sedation; and, 3) Discuss the eventual permissibility of recourse to palliative sedation for existential suffering. In so doing, the authors aim to inform current bioethical debates. **Abstract:** http://bit.ly/2t0XQbE

> **N.B.** Italian language article. Selected articles on terminal (or palliative) sedation noted in 9 September 2019 issue of Media Watch (#643, p.7).

A review of the literature on native Hawaiian end-of-life care: Implications for research and practice

HAWAI'I JOURNAL OF HEALTH & SOCIAL WELFARE, 2019;78(12):41-44. The need for cultural understanding is particularly important in end-of-life care (EoLC) planning as the use of EoLC in minority populations is disproportionately lower than those who identify as Caucasian. Data regarding the use of EoLC services by Native Hawaiians in Hawai'i and the U.S. is limited but expected to be similarly disproportionate as other minorities. In a population with a lower life expectancy and higher prevalence of deaths related to chronic diseases such as cardiovascular disease, diabetes, and obesity, as compared to the state of Hawai'i as a whole, the authors' objective was to review the current literature to understand the usage and perceptions of EoLC planning in the Native Hawaiian population. Available literature highlights the importance of understanding family and religion influences, educating staff on culturally appropriate EoLC communication, and the need for more research on the topic. **Access article at:** http://bit.ly/390mUQF

Cont.

Noted in Media Watch 23 September 2019 (#632, p.16):

- *HAWAII JOURNAL OF HEALTH & SOCIAL WELFARE*, 2019;78(7):236-239. **'Education and end-of-life options: Hawaii's 'Our Care, Our Choice Act.'** As more terminally ill patients become aware of and inquire about the Hawai'i 'Our Care, Our Choice Act,' Hawaii's physicians should be prepared to discuss this option or to refer a knowledgeable consultant. They should help patients make informed choices, while navigating their own personal beliefs and ethical values. Hawaii's medical aid in dying law now provides an option for self-determination; however, this choice must be an educated and unbiased choice by the terminally ill patient, knowing palliative care options are available to provide comfort at the end of life. **Full text:** http://bit.ly/2lRqBnw

A comparison of policy analysis of palliative care for cancer in U.K., Malaysia, and South Africa

INTERNATIONAL JOURNAL OF CANCER MANAGEMENT | Online – 15 December 2019 – National policies play an important role in spreading access to palliative care (PC). One of the factors that distinguish the policies of different countries in supportive and PC provision is the existence and efficiency of a state strategy for national PC. In the U.K., there is a comprehensive strategy for the enhancement and development of national PC. The vision and targets are clarified, and an action plan is defined along with powerful mechanisms in order to achieve these targets. Besides, the strategies are clearly determined by the central government and are regularly assessed and updated, and local governments should follow them. However, in Malaysia and South Africa, despite the fact that there is a governmental strategy and a broad vision of the development and promotion of national PC, the general and the specific goals are not defined and there are limited mechanisms to achieve goals. In these countries, unlike the U.K., the local states are not obliged to follow national strategies. In other words, these strategies are only prescriptive in nature. In these countries, the Ministry of Health is responsible for the stewardship and the policy actions of PC, and regional departments are responsible for implementing these policies. One of the advantages of South Africa is its major role in global issues and a PC statement during the African Union Summit in 2013 issued by the Minister of Health. In 2016, a PC policy framework was also approved. The U.K. owns the highest quality of death as a result of inclusive national policies, the broad integration of PC into national healthcare services, and the powerful hospice movement. It also has the highest score for care quality. Generally, income level is a good indicator of PC accessibility and quality: rich countries such as the U.K. are placed high in the ranking of PC. **Full text:** http://bit.ly/2Mw41ez

Diagnosing gaps in the development of palliative and end-of-life care: A qualitative exploratory study

香港中文大學
The Chinese University of Hong Kong

INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH | Online – Accessed 23 December 2019 – A global report found that the quality of dying in Hong Kong lagged behind that of other high-income economies. This study aims to examine the service gaps by conducting a qualitative exploratory study from multiple stakeholders' perspectives. The authors interviewed 131 participants, including patients, family members, healthcare providers, administrators, lawyers, and policy makers. The situation analysis helped identify the facilitators and barriers at individual, organizational, and socio-cultural levels that affect service development. Findings showed that awareness on palliative and end-of-life care (EoLC) is growing, but the existing care is limited in terms of acceptability, coverage, variation in practices, continuity, and sustainability. A number of policy, economic, socio-cultural, environmental, and legal factors were also found to hinder service development. Findings of this study demonstrated that the development of palliative and EoLC services involved a paradigm shift relating to society as a whole. The overarching theme is to formulate a government-led policy framework. Furthermore, a public health approach has been advocated to create a supportive environment for service development. **Abstract:** http://bit.ly/2PRQsZ2

> **N.B.** Click on pdf icon to access full text. Hong Kong is ranked 22nd of 80 countries surveyed in the '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit (commissioned by the Lien Foundation of Singapore), October 2015. [Noted in 12 October 2015 issue of Media Watch (#431, p.6)] **Download/view at:** http://bit.ly/30YoDkl

Creation of a palliative care advanced practice registered nurse peer-review process

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Online – 19 December 2019 – Advanced practice registered nurses (APRNs) are challenged by their professional organisations to participate in self-evaluation and peer review … a method for evaluating the care provided by the APRN to both ensure quality nursing care and promote professional growth. Despite guidelines to participate in a formal peer-review process, there is little information within the nursing profession on how to accomplish peer review. A comprehensive literature review failed to provide a framework for peer review that is practice focused, fosters a learning environment, and encompasses the thought process and clinical decision-making of the palliative care (PC) advanced practice nurse. A group of PC APRNs set out to create a process that encompassed the breadth of clinical decision-making in PC advanced nursing practice. Using the eight domains of PC, a narrative case review structure was created. The resulting process both assisted the APRNs in professional growth and provided timely feedback for the annual performance evaluation. **Abstract:** http://bit.ly/2sSFNEq

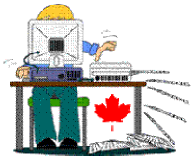
Hospice utilization in the U.S.: A prospective cohort study comparing cancer and non-cancer deaths

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 27 December 2019 – The objectives of this study were to: 1) Provide reliable estimates of hospice use among adults in the U.S.; and; 2) Identify factors predicting use among decedents and within subsamples of cancer and non-cancer deaths. The authors conducted a prospective cohort study using the Health & Retirement Study survey: they used data from the 2012 survey wave to predict hospice use in general, and then separately for cancer and non-cancer deaths. They constructed a sample of 1,209 participants who died between the 2012 and 2014 survey waves. Hospice utilization rate was 52.4% for the sample with 70.8% for cancer deaths and 45.4% for non-cancer deaths. Fully adjusted model results showed being older, less healthy, having dementia, and having cancer were linked to greater odds of receiving hospice. Among cancer deaths, being older and female were the only predictors of hospice use. Among non-cancer deaths, increased age, more education, being widowed, needing help with activities of daily living, and poor health were associated with hospice utilization. Findings suggest hospice remains underutilized, especially among individuals with non-cancer illness. Extrapolating results to the U.S. population, the authors estimate that annually nearly a million individuals who are likely eligible for hospice die without its services. Most (84%) of these decedents have a non-cancer condition. Interventions are needed to increase appropriate hospice utilization, particularly in non-cancer care settings. **Abstract:** http://bit.ly/378HU5Y

Prevalence of unmet palliative care needs in adults with cystic fibrosis

JOURNAL OF CYSTIC FIBROSIS | Online – 17 December 2019 – Physical and emotional burdens impair quality of life (QoL) in many adults with cystic fibrosis (CF). Palliative care (PC) improves QoL in other serious illnesses, yet the full array of palliative needs amenable to PC are unknown in CF. Unmet physical and psychological palliative needs are prevalent in adults with CF. Symptoms are a stronger predictor of needs than physiologic measures... The Supportive Care Needs Survey-34 is a clinically useful tool to evaluate PC needs in CF. **Abstract:** http://bit.ly/2sUrQpq

> **N.B.** Selected articles on the PC needs of people living with CF noted in 9 September 2019 issue of Media Watch (#630, p.8).



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

Chasing hope: When are requests for hospital transfer a place for palliative care integration?

JOURNAL OF HOSPITAL MEDICINE | Online – 18 December 2019 – When seriously ill patients and families consider transfer to a tertiary medical center in a situation of medical crisis, it can be a good time to pause. Palliative care specialists are trained to communicate around these difficult points of transition, but generalist clinicians already involved in the patient's care can also sensitively explore patients' prognostic awareness as it relates to the hospital transfer. The phrases mentioned [by the authors] suggest language that is helpful in broaching such discussions, which assesses the patient's illness understanding, hopes, and worries. Asking about patients' hopes for their illness enables clinicians to quickly know some of their most important priorities. Giving patients the permission to be future-oriented and positive also supports them to cope in these challenging conversations. Asking patients to identify two or three hopes places their most optimistic hopes within a larger context and can lead to a discussion of the potential tradeoffs of the transfer. For example, the hope for a little more time from treatments available through transfer may be at odds with the hope to spend as much time as possible with family. Once the patient's hopes are better understood, the clinician can then ask about worries. Most seriously ill patients are deeply (often silently) worried about the future, and when asked, can articulate worries about dying that can be the foundation for an honest conversation about the likely course of the hospital transfer. **Full text:** http://bit.ly/2ERhny2

Related:

- *CANCER* | Online – 20 December 2019 – **'Potentially burdensome end-of-life transitions among nursing home residents with poor-prognosis cancer.'** Nursing home (NH) residents with advanced cancer have substantial co-morbidities and functional impairment, yet more than a third experience potentially burdensome end-of-life (EoL) transitions. A potentially burdensome transition was defined as two or more hospitalizations or an intensive care unit admission in the last 90 days life. The findings of this analysis of 34,670 deceased NH residents with poor-prognosis solid tumors … helped to identify a population at risk for poor EoL outcomes in order to target interventions, and they point to the importance of advanced care planning in this population. **Abstract:** http://bit.ly/2ZoeYEj

The relationship of palliative care with assisted dying where assisted dying is lawful: A systematic scoping review of the literature

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 24 December 2019 – A central approach of palliative care (PC) has been to provide holistic care for people who are dying, terminally ill or facing life-limiting illnesses while neither hastening nor postponing death. Assisted dying laws allow eligible individuals to receive medically administered or self-administered medication from a health provider to end their life. The implementation of these laws in a growing number of jurisdictions therefore poses certain challenges for PC. The authors analyzed the research literature about the relationship of assisted dying with PC, in countries where it is lawful. After reviewing 5,778 references from searches, 105 were subject to full-text review. Sixteen studies were included: from Belgium (4), Canada (1), Switzerland (2) and the U.S. (9). The authors found the relationship between assisted dying and PC practices in these locations took varied and sometimes combined forms: supportive, neutral, coexisting, not mutually exclusive, integrated, synergistic, cooperative, collaborative, opposed, ambivalent and conflicted. The studies in this review cast only partial light on challenges faced by PC when assisted dying is legal. There is pressing need for more research on the involvement of PC in the developing practices of assisted dying, across a growing number of jurisdictions. **Abstract:** http://bit.ly/2ZoBSLR

Noted in Media Watch 2 December 2019 (#642, p.1):

- CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION (CHPCA) & CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS (CSPCP) | Online – 27 November 2019 – **'Joint statement regarding palliative care and medical assistance in dying.'** The CHPCA and the CSPCP seek to clarify the relationship of hospice palliative care (HPC) and medical assistance in dying (MAiD). Healthcare articles and the general media continue to conflate and thus misrepresent these two fundamentally different practices. MAiD is not part of HPC; it is not an "extension" of palliative care nor is it one of the tools "in the palliative care basket."; National and international HPC organizations are unified in the position that MAiD is not part of the practice of hospice. **Download/view at:** http://bit.ly/33mmIad

Letting go: A writing exercise and a discussion

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 18 December 2019 – As palliative care clinicians, we help care for patients who are always very sick, and oftentimes are dying. We break a lot of bad news. We give prognoses that are usually far shorter than our patients or their family members believe to be true, and every time shorter than they want to be true. Sometimes, we become the target of their anger, as it ensues. This work is a calling, not a vocation, or most of us would leave. **Abstract:** http://bit.ly/2MjcBxm

"There's just no way to help, and they did." Parents name compassionate care as a new domain of quality in pediatric home-based hospice and palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 27 December 2019 – To design high-quality home-based hospice and palliative care (HBHPC) systems, it is imperative to understand the perspectives of parents whose children enroll in HBHPC programs. This was a qualitative study utilizing semi-structured interviews of bereaved parents of children who were enrolled in a pediatric HBHPC program at the three sites [across Ohio] from 2012 to 2016 and parents of children who were currently enrolled in these programs for at least a year. Parent-prioritized thematic codes mapped to 9 of the 10 provider-prioritized domains of quality HBHPC; none mapped to the domain "Ethical and Legal Aspects of Care." Although most of the provider-prioritized domains are pertinent to parents, parents defined these domains differently, deepening understanding and perspective of quality within each domain. An 11th domain, Compassionate Care, was created and defined based on emergent themes. Parents also prioritize Compassionate Care as a new domain of quality in pediatric HBHPC. Measuring the quality of care provided in HBHPC programs through this broader perspective should enable the selection of measures which are truly patient- and family-centered. **Abstract:** http://bit.ly/2t6eG9c

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 December 2019 – **'Hospital or home? Where should children die and how do we make that a reality?'** Most of the 20,000 US children dying of serious illnesses annually die in the hospital. To better understand location of death preferences in North America, the authors reviewed the literature to examine the evidence for and against home death in seriously ill children (0-18 years). The authors' findings should be interpreted with several caveats: 1) Many studies are small and prone to selection bias; 2) Not all families prefer home death and some that do are not able to achieve home death due to inadequate home support; and, 3) Studies of bereavement outcomes are lacking. **Abstract:** http://bit.ly/350tcMJ

The perception of barriers concerning opioid medicines: A survey examining differences between policy makers, healthcare professionals and other stakeholders

PALLIATIVE MEDICINE | Online – 23 December 2019 – Numerous studies have reported on barriers to access, including patients' reluctance to use opioids, inadequate staff knowledge of pain management and complicated regulations. Most studies focused on patients, physicians or nurses; only a few studies examined the perception of barriers among policy makers. There are no studies comparing policy makers and healthcare professionals working in the field of harm reduction, pain management and palliative care. Most frequently rated major barriers included lack of financial resources and inadequate knowledge, skills and training among policy makers. Issues were least often seen as a major barrier by policy makers and most often by harm reduction professionals. Significant differences between stakeholder groups were identified on specific aspects, such as excessive regulation or bureaucracy for prescribing. Multiple barriers may play an important role, partly depending on the perspective of the stakeholder involved. Potential negative consequences of control measures for healthcare professionals and patients may not always be recognized by the stakeholders who draft these policies. To implement widely supported solutions, it is important to include all stakeholders, taking into consideration their different perceptions. **Full text:** http://bit.ly/34RxB4A

Hospital-based bereavement care provision: A cross-sectional survey with health professionals

PALLIATIVE MEDICINE | Online – 23 December 2019 – An in-hospital death is a profound experience for those left behind and has been associated with family members' psychological morbidity. Supporting bereaved family members is an essential part of end-of-life care and includes attentive presence, information-giving, and emotional and practical support. The actual adoption of hospital-based bereavement care, however, remains little understood. This study indicates that many barriers to bereavement care exist in hospitals. More research is required to better understand enabling and limiting factors to bereavement care provision. A guideline-driven approach to hospital-based bereavement care that defines best practice and required organizational support seems necessary to ensure needs-based bereavement care. **Abstract (w. list of references):** http://bit.ly/35SZxXj

Noted in Media Watch 20 August 2019 (#577, p.11):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 15 August 2018 – **'Filling the void: Hospital palliative care and community hospice – collaborative approach to providing hospital bereavement support.'** This practice concept article describes an innovative bereavement program designed to offer support to individuals whose loved one died in the hospital while receiving palliative care. The bereavement team … developed the University of Florida Health Bereavement Program. The program incorporates grief support workshops, follow-up with participants, via postal mail at timed intervals, website access to grief resources, staff education, and an annual evening of remembrance program. **Abstract (w. link to references):** http://bit.ly/2EPU6wj

Puente para cuidar (bridge to caring): A palliative care patient navigator and counseling intervention to improve distress in Latino/as with advanced cancer

PSYCHO-ONCOLOGY | Online – 13 December 2019 – A culturally adapted intervention to address mental health and palliative care needs in Latino/as with advanced cancer was developed from prior evidenced-based interventions using a cultural adaptation model and a participatory approach. Adaptations were made to language, literacy, and content of the counseling intervention, and video vignettes of the counseling case studies were produced on the recommendation of Latino stakeholders. Bicultural, bilingual patient navigators were used as "cultural brokers" between Latino patients and the counselor. The pilot study of *puente para cuidar* demonstrated feasibility based on participant perception of helpfulness and acceptability and nearing goal visit completion rates. The intervention is ready for effectiveness testing. **Abstract:** http://bit.ly/2Su7FJS

N.B. Selected articles on patient navigators in the context of palliative care noted in 14 January 2019 issue of Media Watch (#597, pp.18-19).

Reconsidering early parental grief following the death of a child from cancer: A new framework for future research and bereavement support

SUPPORTIVE CARE IN CANCER | Online – 24 December 2019 – Parents of children that die from cancer are at increased risk of significant long-term psychosocial and physical morbidities. Less, however, is known about the experience of parents early in the grief process. Currently used frameworks and instruments used to understand and assess outcomes in parents early in the grief experience are inadequate and may serve to pathologize the normal grief response. Through review of the literature, previously conducted qualitative work, and extensive clinical experience working with bereaved parents, the authors developed a new framework for understanding, assessing, and studying parental grief during the first two years following the death of a child from cancer. Their novel longitudinal framework hypothesizes that short- and long-term psychosocial sequalae in parents following the death of a child from cancer depend not only on pre-death factors but on the support present through the disease experience and the oscillation between protective factors and risk factors in the post-death period. The authors further hypothesize that protective factors and risk factors may be modifiable, making them key potential targets for suppor-

Cont.

tive interventions aimed at augmenting protective factors and diminishing the effect of risk factors. This is a new framework for understanding and assessing the grief experience of parents within the first two years of a child's death. Many questions about how best to support parents following the death of a child from cancer remain providing ample opportunities for future research and development of interventions to improve both short- and long-term outcomes in bereaved parents. **Abstract (w. list of references):** http://bit.ly/35VSv41

CANADIAN Virtual Hospice | Portail CANADIEN EN SOINS palliatifs

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

Dying well-informed: The need for better clinical education surrounding facilitating end-of-life conversations

YALE JOURNAL OF BIOLOGY & MEDICINE, 2019;92(4):757-764. The need for improved clinical education surrounding the way difficult news is delivered and how to initiate end-of-life (EoL) discussions with seriously ill patients and their families is essential. Physicians and medical students often report feeling unprepared or uncomfortable with broaching the topic of death with their patients and families. Early and honest conversations with patients concerning diagnoses and advance directives help patients and their families make well-informed decisions regarding future medical care, minimize pain and fears, and allow patients to experience a "peaceful death." Moreover, EoL conversations frequently focus on resuscitation plans (e.g., advance directives), but should be broadened to include patients' psychosocial, physical, and economic concerns. Transparent, realistic, and sensitive EoL conversations can help patients maintain autonomy and dignity in the dying process and increase their quality of life as they near death. Additionally, initiating these conversations can alleviate emotional stress and physical symptoms, prevent invasive, costly, unnecessary, and unwanted care, aid grieving families through the bereavement process, and increase patients' satisfaction with EoL care provisions. Overall, more attention and training must be delivered to physicians so that they are better prepared to initiate EoL discussions in a patient-centered way, focusing on patients' values and priorities. Requiring a more in depth, developmentally appropriate, and standardized training in EoL and palliative care for physicians-in-training in all disciplines in medical education is necessary. **Full text:** http://bit.ly/39nwLjI

Death is ubiquitous and inevitable

YALE JOURNAL OF BIOLOGY & MEDICINE, 2019; 92(4):573-574. Many of us have had some experience with death in our personal lives, and as clinicians and researchers, we address death either directly or indirectly, almost every day. Still, there remains significant debate and gaps in knowledge regarding the biology of death, as well as the medical and ethical issues concerning death and dying. This multidisciplinary issue of the journal is devoted to exploring the major advances and unresolved questions about death. **Journal contents page:** http://bit.ly/36XoEs2

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL OF MEDICAL ETHICS* | Online – 23 December 2019 – **'Experiences with counselling to people who wish to be able to self-determine the timing and manner of one's own end of life: A qualitative in-depth interview study.'** This study confirms the idea that having the means available to be able to end your own life in a respectable manner can provide people with reassurance and can increase their quality of life. It can, however, also give rise to new concerns like worrying about the shelf-life of medication or not losing the medication. This study also makes clear that counselling entails more than just providing information on (collecting) medication. Counsellors can play an important role for people who wish to self-determine the timing and manner of their end of life (EoL), by having an open non-judgemental attitude, providing trustworthy information and being available. These positively valued aspects of de-medicalised assistance in suicide can provide recommendations for physicians taking care of patients who wish to self-determine the timing and manner of their EoL. **Full text:** http://bit.ly/34OHtvT

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.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

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

Media Watch: Access on Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://bit.ly/2OVQyP3

[Scroll down to ‘Media Watch: The Homeless’]

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://bit.ly/2ThijkC

PALLIATIVE CARE NETWORK: http://bit.ly/2Ujdk2S

PALLIMED: http://bit.ly/2ResswM

[Scroll down to ‘Media Watch by Barry Ashpole’; also ‘Media Watch: Behind the Scenes’ at: http://bit.ly/2MwRRAU]

Australia

PALLIATIVE CARE RESEARCH NETWORK: http://bit.ly/2E1e6LX

[Click on e-News (November 2019); scroll down to ‘Useful Resources in Palliative Care Research’]

Cont.

Canada

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

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

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

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): http://bit.ly/2XC24jA

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

---

Barry R. Ashpole, Ontario CANADA **e-mail: barryashpole@bell.net**