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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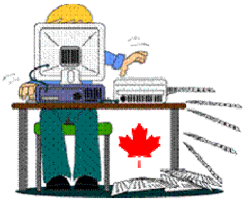

Compiled & Annotated by Barry R. Ashpole

A cultural shift in how we talk about death and dying is required to facilitate acceptance and understanding of what palliative care is and how it can improve people's lives.

'Embedding palliative approaches to care in long-term care' (p.10), in *Canadian Nurse*.

Canada

British Columbia cuts funding for hospice operator that won't provide medically assisted death

BRITISH COLUMBIA | CTV News (Vancouver) – 25 February 2020 – A hospice operator in Metro Vancouver is losing out on roughly $1.5 million in annual funding after refusing to provide patients access to medically assisted death. Every hospice in British Columbia that receives more than half its funding from the government is required to provide assisted dying service for patients who request it – but the Delta Hospice Society has dug in its heels, arguing that doing so would go against its principles. That standoff resulted in an ultimatum from the Fraser Health Authority late last year, and the provincial government announced plans to terminate its contract with the hospice operator. The government said funding for the society will dry up on 25 February 2021, which gives the operator the 365 days' notice required to end its agreement "without cause." The society runs a small, 10-bed facility called the Irene Thomas Hospice on a parcel of land in Delta that's owned by Fraser Health. The government promised the health authority will continue to ensure local residents "continue to have access to those beds" after the society's contract is up. http://bit.ly/2Tn6rPA

Specialist Publications

'The rocks and hard places of medical assistance in dying (MAiD): A qualitative study of nursing practice in the context of legislated assisted death' (p.14), in *BMC Nursing*.

'Suicide attempt following determination of ineligibility for assisted death: A case series' (p.14), in *Journal of Pain & Symptom Management*.

N.B. Press coverage regarding Delta Hospice Society noted in 20 January 2020 issue of Media Watch (#649, p.2). Download/view the Society's press release issued 28 February 2020 in response to the provincial government's decision to withdraw funding at: http://bit.ly/2Vz7Xkk

Would this article be of interest to a colleague?

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online – 24 February 2020 – **'Liberals table legislation to expand access to assisted dying.'** The Liberal government has tabled legislation to amend the rules on medical assistance in dying (MAiD), repealing the requirement that a person's natural death be "reasonably foreseeable" and disqualifying those whose sole underlying condition is a mental illness. The proposed changes also would permit access to MAiD to someone whose death is reasonably foreseeable – but who has lost the capacity to consent since deciding to do so through an agreement with a medical or nurse practitioner. The bill removes the requirement for a 10-day "reflection period" and waives the requirement that a patient provide final consent. Since MAiD became legal in Canada in June 2016, there have been more than 13,000 medically assisted deaths, according to background material provided by Justice Canada. The bill arrived after the government launched an online survey on MAiD and held roundtables in cities across the country. The survey drew about 300,000 responses. Canada's existing MAiD law requires a parliamentary review and a study of the state of the palliative care in Canada by June 2020. http://bit.ly/38YmFoT

U.S.A.

The cost of dying in the U.S. is exorbitant. Behavioral economics explains why.

FORBES | Online – 25 February 2020 – Currently, 1% of patients accounts for more than 20% of U.S. healthcare spending. Despite efforts to provide hospice services to people near the end of life (EoL), many people are not admitted to hospice until just days before their death. In short, we spend lots of money on EoL care even when that spending – and the services we provide–don't improve the length or quality of people's lives. Behavioral economics offer some insights into these high-spending ways, insights we need to draw upon if we hope to improve EoL care and reduce EoL spending. Our approach so far as a society to combat the high cost of EoL care has been to gently tweak the financial incentives facing healthcare providers. A touch of capitation, a dash of accountable care. This is a fine start, without a doubt. But it won't be enough, not given the powerful psychological and economic forces influencing people at the EoL. To reduce EoL costs, we need to recognize and account for the concerns of patients and families facing tragic choices. http://bit.ly/2PpeMkA

Specialist Publications

'Matters of life and death: Why do older patients choose conservative management?' (p.4), in *American Journal of Nephrology.*

'Life-sustaining treatment decisions initiative: Early implementation results of a national Veterans Affairs program to honor veterans' care preferences' (p.7), in *Journal of General Internal Medicine.*

Hospices can build financially sustainable palliative care programs

HOSPICE NEWS | Online – 24 February 2020 – Hospices provide 50% of the community-based palliative care (PC) delivered in the U.S.,[1] but many find it challenging to make their programs profitable or break even, often relying on philanthropy to support their efforts. However, some organizations are implementing innovative models and developing payer relationships that can turn that trend around. Interest in PC is growing among healthcare providers, payers and policymakers due to the substantial potential savings in healthcare costs and the need to care for an aging population, a high proportion of which suffers from serious or chronic illness. PC consultations can reduce direct hospital costs by $3,000 per patient admitted, and up to $4,800 per admission for patients suffering from four or more diagnoses...[2] It can also reduce the frequency of 911 calls, emergency department visits, and unnecessary hospitalizations. Home-based PC could reduce societal healthcare costs by $103 billion within the next 20 years, the non-profit economic research group Florida TaxWatch said in a report.[3] http://bit.ly/390wylL

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

2. ‘Economics of palliative care for hospitalized adults with serious illness: A meta-analysis,’ *JAMA Internal Medicine*, 2018;178(6):820-829. [Noted in 11 June 2028 issue of Media Watch (#567, p.9)] **Full text:** http://bit.ly/2TgDcO6

3. ‘Palliative care in Florida: Challenges and options for Florida’s future,’ TaxWatch, March 2019. [Noted in 8 April 2019 issue of Media Watch (#609, p.2)] **Download/view at:** http://bit.ly/2OT8Iiu

International

Disability Royal Commission looks at palliative care for people with intellectual disabilities

AUSTRALIA | ABC News – 26 February 2020 – Palliative care (PC) and the way it’s used for people with intellectual disabilities (IDs) has come up at the Disability Royal Commission... PC, of course, is for those with life-limiting or terminal illnesses, where other treatments have been exhausted. But the evidence lifted the lid on the use of PC for people with IDs who’ve had no prior treatment – people who die, but could have been saved. It continues a week of evidence about serious failures in the Australian health system in its treatment of people with IDs. https://ab.co/32w9XuM

> **N.B.** Additional articles on PC for people living with IDs noted in 24 February 2020 issue of Media Watch (#654, p.8). See also ‘Current thinking on palliative and end-of-life care for patients living with intellectual and developmental disabilities,’ European Association for Palliative Care blog: http://bit.ly/300WMRt

Specialist Publications

‘Instability in end-of-life care preference among heart failure patients: Secondary analysis of a randomized controlled trial in Singapore’ (p.6), in *Journal of General Internal Medicine*.

‘European palliative sedation project’ (p.9), in *Journal of Palliative Medicine*.

‘Making end-of-life and palliative care viable in India: A blueprint for action’ (p.13), in *National Medical Journal of India*.

‘Towards person-centred quality care for children with life-limiting and life-threatening illness: Self-reported symptoms, concerns and priority outcomes from a multi-country qualitative study’ (p.12), in *Palliative Medicine.*

Share this issue of Media Watch with a colleague

Arabic translation of ‘Elderly & End-of-Life Care for Muslims in the U.K.’ available online

U.K. | Muslim Council of Britain – 23 February 2020 – Part 3 of ‘Elderly & End-of-Life Care for Muslims in the U. K.,’ pp.36-41, presents perspectives on palliative and end-of-life care (EoLC) from the analysis of interviews with patients, families, healthcare professionals, imams and other relevant stakeholders. The evidence points to an unmet need amongst Muslims of EoLC. It notes some of the positive responses in hospitals and hospices but calls for greater religious literacy amongst service providers. The findings also emphasise the need for a culture change, led by Imams, to raise issues of death and dying that can increase awareness of palliative and EoLC services and help counter the cultural stigma in the accessing of services. Evidence suggests there is a schism between the current model of EoLC and the health needs of religious and ethnic communities. Such evidence includes reports that point to an unmet need amongst Muslims of EoLC. This is reflected in poor uptake of advanced care planning and hospice services, in-

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cluding community-based services and on-site care. Reports also suggest that services are not adequately equipped to provide care for religious-ethnic minorities, whose spiritual needs are central to their EoLC. There is a growing concern that a lack of understanding in relation to what course of management is considered appropriate for minority populations, in the U.K., may lead to confusion, misunderstanding, unnecessary conflict, or even unseemly clinical events. **Download/view at:** http://bit.ly/2zvuZw4

> **N.B.** The English language version of the Muslim Council of Britain report was first noted in 2 September 2019 issue of Media Watch (#629, p.4). Additional articles on the Islamic perspective on end of life and palliative and EoLC noted in 17 June 2019 issue of Media Watch (#618, p.10).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GERMANY | *The Jurist* – 26 February 2020 – **'Germany Constitutional Court overturns ban on professionally-assisted suicide.'** The ruling overturns a previous ban on professionally-assisted suicide. Section 217 of the German Criminal Code previously provided punishments of up to three years of imprisonment or a fine to anyone who, with the intention to help another individual commit suicide, provided the opportunity through either personally providing or procuring the professional services. The law was meant to protect "autonomy and life," but the court found that it exceeds "the limits of what constitutes a legitimate means for protecting personal autonomy in the decision on ending one's life where it no longer protects free decisions of the individual but renders such decisions impossible." The court found that the law violated the constitution, and had to be declared void. The court held that the right to professionally-assisted suicide is not limited to serious or incurable illnesses or to certain stages of life. It is guaranteed in all stages of life and condition. Individuals also have the right to seek assistance from third parties. http://bit.ly/2vmCjeT

Specialist Publications

Matters of life and death: Why do older patients choose conservative management?

AMERICAN JOURNAL OF NEPHROLOGY, 2020;51(1):35-42. Although many older patients with end-stage renal disease and limited prognoses prefer conservative management (CM), it is not widely offered in the U.S. Moreover, there is a dearth of U.S.-based literature reporting clinical experience with shared decision-making regarding CM of advanced chronic kidney disease (CKD). The authors describe the clinical experience of 13 patients who opted for CM at the University of Rochester Medical Center's CKD clinic during 2016-2017. Main outcomes include: 1) Reason for choosing CM; 2) Completion of advance directives; 3) Location of death; and, 4) Utilization of hospice service. Patients' reasons for choosing CM were categorized into four broad categories based on a review of their electronic medical records. A retrospective chart review conducted by two reviewers determined the status of advance care planning, hospice referral, and place of death. The reasons for choosing CM included: poor prognoses, a wish to maintain their quality of life, their desire for a dignified life closure, and the intention to protect family members from having to see them suffer, based on their own memory of having witnessed a relative on dialysis previously. Promoting the choice of CM in the U.S. will require training of clinicians in primary palliative care competencies, including communication and decision-making skills, as well as basic symptom management proficiencies. **Abstract (w. list of references):** http://bit.ly/33qZy2w

A scoping review of initiatives to reduce inappropriate or non-beneficial hospital admissions and bed days in people nearing the end of their life: Much innovation, but limited supporting evidence

BMC PALLIATIVE CARE | Online – 27 February 2020 – There is much innovation happening to improve end-of-life (EoL) care. Evidence as to whether it reduces inappropriate or non-beneficial hospital utilisation is limited, sometimes contradictory and of variable quality. Many people working in palliative care (PC) are convinced that what they are doing can benefit patients and families through a reduction in un-

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necessary and burdensome EoL hospital admissions, but do not have robust evidence to prove it. Where success is claimed, little is known about why an initiative worked and how it might be successfully transposed elsewhere. It is worth restating that not all bed days are "bad" or unwanted by patients and families. As so often in PC, further research is required. A notable example is the area of ambulance and paramedic education. It is hoped that the ongoing quantitative and qualitative HOspice-Led Innovations Study To Improve Care (HOLISTIC) study, which looks at patient journeys toward the EoL by mapping Hospital Episode Statistics data against stakeholder interviews, may provide further insights. **Full text:** http://bit.ly/2T5rh75

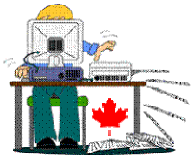
Compassion fatigue, watching patients suffering and emotional display rules among hospice professionals: A daily diary study

BMC PALLIATIVE CARE | Online – 25 February 2020 – Hospice care professionals (HCPs) work constantly in an emotionally challenging context and are vulnerable to compassion fatigue, burnout and emotional related issues. The main purpose of this study was to examine the relationship between daily fluctuations in seeing patient suffering and daily emotional work display, and to assess whether compassion fatigue (secondary traumatic stress and burnout) moderate this between-person relationship. At the between-person level, results from this study were in line with previous research that showed how emotionally demanding jobs entail a higher frequency and intensity of daily interactions with patients and families that in turn requires regular use of emotional labour regulation. In this sense, on days where HCPs witness suffering patients frequently, they will regulate their positive emotional display. In this sense, regular use of emotional labour regulation strategies can expose HCPs to reduced well-being. The results of this study are in line with traditional studies that demonstrate how emotional connections are a vital component of the therapeutic relationship in the hospice context, expressing their feelings when healing suffering is a fundamental part of this relationship. Additionally, in relation to the cross-sectional moderation effect, the authors found that burnout moderated the within-person relationship between seeing patients suffering, and daily emotion work display such that this relationship was stronger for those high in burnout. **Full text:** http://bit.ly/2PseJUV

N.B. Additional articles on compassion fatigue and the well-being and resilience practices in hospice and palliative care noted in 27 January 2020 issue of Media Watch (#650, p.7).

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 February 2020 – **'Frequency of burn-out among palliative care physicians participating in a continuing medical education (CME) course.'** Of 110 physicians, 83% completed a survey. Palliative care (PC) was practiced 50% of the time by 62%... 80% reported that PC is appreciated at their work, 64% reported insurance to be a burden, and 64% reported the Electronic Medical Record was a burden. 90% felt optimistic about continuing PC in the future. Burnout among PC physicians who attended a board review course was 38%. Physicians who choose to attend CME may have unique motivating characteristics allowing them to better cope with stress and avoid burnout. **Abstract (w. link to references):** http://bit.ly/2HZIZCx



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

Palliative care for dementia: 2019 update

CLINICS IN GERIATRIC MEDICINE | Online – 20 February 2020 – Dementia management is complicated by neuropsychiatric symptoms such that the longitudinal care of a psychiatrist or other mental health provider is often an essential part of patient care and a major source of family support. Given the importance of end-of-life continuity of care, the involvement of psychiatry in palliative and hospice services affords an important opportunity for growth. Common challenges involve sharing prognostic information with patients and families to aid in advance planning, and management of persistent pain and nutritional issues. Future research will yield important new insights and guidelines for care. **Abstract (w. link to references):** http://bit.ly/2wNiH40

Noted in Media Watch 24 February 2020 (#654, p.12):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 20 February 2020 – **'Dying with dementia: Caregiver observations of their family members' physical decline and behavioral or psychological changes during their last days.'** This qualitative study of 30 caregivers of family members aged 65 years and older who died with dementia-related diagnoses used in-depth qualitative interviews conducted over a 12-month period and directed content analysis to understand the data. The study asked what physical, behavioral, and psychological changes they observed and experienced during their family members' last weeks of life. Three primary themes were identified around behavioral and psychological changes. **Abstract (w. list of references):** http://bit.ly/2VacSrA

- *PALLIATIVE MEDICINE* | Online – 17 February 2020 – **'Case series of introducing palliative care consultation in psychiatry.'** The author analyzes the introduction of palliative care (PC) consultation in a large psychiatric hospital. PC consultation was established and details including patient age, department, diagnosis, main problem, solution and discharge were analysed during the first two years. Two consultations in the first year and 18 consultations in the second year were requested involving delirium associated with dementia or another condition and mental illness (e.g., alcoholic psychosyndrome, psychosis, suicidal tendency, schizophrenia, depression), and cancer (25%). Recommendations of consultations were realized in 95%. **Abstract (w. list of references):** http://bit.ly/38BEWIn

N.B. Additional articles on: PC for people living with dementia noted in 10 February 2020 issue of Media Watch (#652, pp.11-12); and, on the role of psychiatry in PC also noted in 24 February 2020 issue of Media Watch (#654, pp.13-14).

Instability in end-of-life care preference among heart failure patients: Secondary analysis of a randomized controlled trial in Singapore

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 26 February 2020 – Efforts to improve quality of end-of-life (EoL) care are increasingly focused on eliciting patients' EoL preference through advance care planning (ACP). However, if patients' EoL preference changes over time and their ACP documents are not updated, these documents may no longer be valid at the time EoL decisions are made. Two hundred eighty-two patients with heart failure (HF) and New York Heart Association Classification III and IV symptoms were recruited and interviewed every 4 months for up to 2 years to assess their preference for EoL care. Nearly two thirds (64%) of patients changed their preferred type of EoL care at least once. Proportion of patients changing their stated preference for type of EoL care increased with time and the change was not unidirectional. Patients who understood their prognosis correctly were less likely to change their preference from non-aggressive to aggressive EoL care or to prefer aggressive EoL care. On the other hand, patient-surrogate discussion of care preference was associated with a higher likelihood of change in patient preference from aggressive to non-aggressive EoL care. This study provides evidence of instability in HF patients' stated EoL care preference. This undermines the value of an ACP document recorded months before EoL decisions are made unless a strategy exists for easily updating this preference. **Abstract (w. list of references):** http://bit.ly/32yUfz8

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Related:

- *BMC NEPHROLOGY* | Online – 19 February 2020 – **'Supporting quality care for end-stage renal disease patients: The social worker can help address barriers to advance care planning.'** The authors outline the clinical, technical, and social barriers to collecting and using the psychosocial information required to perform advance care planning (ACP). Their goal is to equip nephrology care teams with information concerning the benefits of ACP, insights on the known barriers to ACP, and strategies to address them. Designing and executing ACP interventions that help to identify ACP perceptions and barriers is an important initial step, and social workers should be at the forefront of implementing ACP in their advocacy for patients and their families. **Full text:** http://bit.ly/2urjG9m

- *BRITISH JOURNAL OF HOSPITAL MEDICINE* | Online – 25 February 2020 – **'Advance care planning: The who, what, when, where and why.'** National Health Service (NHS) England has outlined a commitment to end-of-life (EoL) care, advocating a shift towards more patient-centred care. The NHS is encouraging the workforce to engage patients in conversations about what is important to them, shifting the focus from "what is wrong with you" to "what matters to you." Traditionally, this was seen as the doctor's role but this conversation can and should happen with the wider skilled medical workforce. The key to advance care planning is to have these conversations early on when patients have the capacity to discuss their preferences for care. **Abstract:** http://bit.ly/32rti0t

- *DEATH STUDIES* | Online – 25 February 2020 – **'Young adults' perspectives on advance care planning: Evaluating the Death-over-Dinner initiative.'** The authors investigated whether attending a Death-over-Dinner (DoD) event affects perspectives on advance care planning (ACP). Participants were assigned to a DoD or waitlist control condition, completing pre-test and post-test measures. Higher Death Rejection and having more Experience with Death predicted Reservations about ACP. Participation in a DoD decreased Reservations toward ACP compared to the control group. DoD appears to be useful in ameliorating reservations toward ACP without shortening individuals' sense of their time left to live. **Abstract:** http://bit.ly/2TgYbjT

Life-sustaining treatment decisions initiative: Early implementation results of a national Veterans Affairs program to honor veterans' care preferences

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 24 February 2020 – On 1 July 2018, the Veterans Health Administration (VA) National Center for Ethics in Health Care implemented the Life-Sustaining Treatment Decisions Initiative (LSTDI). Its goal is to identify, document, and honor LST decisions of seriously ill veterans. Providers document veterans' goals and decisions using a standardized LST template and order set. LST templates were documented for 108,145 veterans, and 85% had one or more of the non-required fields completed in addition to the required fields. Approximately half documented a preference for cardiopulmonary resuscitation. Among those who documented specific goals, half wanted to improve or maintain function, independence, and quality of life while 28% had a goal of life prolongation irrespective of risk of hospitalization/death and 45% expressed a goal of comfort. Only 7% expressed a goal of being cured. **Abstract (w. list of references):** http://bit.ly/2PnNpqL

Witnesses of hope in times of despair: Chaplains in palliative care

JOURNAL OF HEALTH CARE CHAPLAINCY | Online – 22 February 2020 – Hope is an important topic in spiritual care in palliative care (PC) but the experiences of chaplains with hope have hardly been explored. The objective of this qualitative study was to explore Dutch chaplains' experiences with hope in PC. Semi-structured interviews were conducted, which were thematically analyzed. The 10 chaplains had a variety of ordinations: Muslim, Protestant, Roman Catholic, Humanistic, or otherwise. Participants spoke about changes in patients' hope, often implying despair and surrender, in which patients' self-reflection was pivotal. They felt witnesses of hope, not by offering hope, but by acknowledging patients hope and despair while being with their patients. They criticized other professionals who, not bearing witness to these experiences, tried to offer hope to patients. The authors conclude that chaplains may become witnesses of hope in times of despair, which includes the (ideological) critical function of spiritual care. **Abstract:** http://bit.ly/2PqV1cm

An investigation of the challenges to coordination at the interface of primary and specialized palliative care services in Switzerland: A qualitative interview study

JOURNAL OF INTERPROFESSIONAL CARE | Online – 26 February 2020 – Good coordination of healthcare services is vital for ensuring health cost efficiency and high-quality care for patients. It is especially important in the context of palliative care (PC) as services are often highly fragmented due to a combination of diverse professional groups, organizations, and approaches to care. However, the coordination of services in this field is often evaluated as insufficient. Little is known about the challenges to coordination in this sector in Switzerland. The present study addresses this gap in research by investigating the challenges to coordination at the interface of PC services in Switzerland. Interviews with 38 healthcare practitioners working in PC in four cantons … form the basis for this investigation. The selected cantons not only represent French, Italian, and German language regions of Switzerland but also represent diverse rural, urban, and historical contexts. Three clusters of challenges to coordination were identified: 1) Organizational challenges to coordination, which relate to explicit forms of coordination; 2) Relational challenges to coordination; and, 3) Structural challenges to coordination, which relate to implicit forms of coordination. The study reveals a need for better financial support for coordination in PC and a stronger focus on interprofessional coordination in educating professionals in PC. Future research on how to further foster good team coordination practices between primary and specialized palliative services merits further investigation. **Abstract:** http://bit.ly/2wfswHB

Top ten tips palliative care clinicians should know about amyotrophic lateral sclerosis

JOURNAL OF PALLIATIVE MEDICINE | Online – 26 February 2020 – Amyotrophic lateral sclerosis (ALS) is a rapidly progressive and fatal neurodegenerative disorder with enormous palliative care (PC) needs that begin at the time of diagnosis. Although it is an uncommon disease, clinicians who work in PC or hospice are likely to encounter ALS somewhat frequently given the needs of patients with ALS with regard to psychosocial support, symptom management, advance care planning (ACP), caregiver support, and end-of-life care. As such, PC clinicians should be familiar with the basic principles of ALS symptoms, treatments, disease course, and issues around ACP. This article, written by a team of neurologists and PC physicians, seeks to provide PC clinicians with tips to improve their comfort and skills caring for patients with ALS and their families. **Abstract:** http://bit.ly/32v8KEl

Noted in Media Watch 24 February 2020 (#654, p.10):

- *JOURNAL OF PALLIATIVE CARE* | Online – 17 February 2020 – **'Engaging specialist palliative care in the management of amyotrophic lateral sclerosis: A patient-, family-, and provider-based approach.'** Stakeholders' [i.e., study participants'] general impressions of specialist palliative care (PC) were highly variable. Many expressed limited or inaccurate understandings of PC's definition and purpose. Perceptions of PC as hospice were common. Stakeholders generally supported the integration of specialist PC into amyotrophic lateral sclerosis (ALS) management, and many recognized the value of early integration of palliative services in both the community and the clinical setting. **Abstract (w. list of references):** http://bit.ly/3bGBi1E

N.B. Additional articles on PC for people living with ALS noted in this issue of Media Watch.

Palliative care and hospice referrals in patients with decompensated cirrhosis: What factors are important?

JOURNAL OF PALLIATIVE MEDICINE | Online – 24 February 2020 – Palliative care (PC) and hospice care are underutilized for patients with end-stage liver disease, but factors associated with these patterns of utilization are not well understood. The authors examined patient-level factors associated with both PC and hospice referrals in patients with decompensated cirrhosis (DC) at a single tertiary center and followed for one year. Of 397 patients, 61 (15.4%) were referred to PC, 71 (17.9%) were referred to hospice, and 99 (24.9%) were referred to PC and/or hospice. PC referrals were late in 68.5% of cases, and hospice referrals were late in 62.7%. Late PC referrals were associated with younger age and married status. Late hospice referrals were associated with younger age and recent alcohol use. **Abstract:** http://bit.ly/2HQsGb4

European palliative sedation project

JOURNAL OF PALLIATIVE MEDICINE, 2020;23(2):153. Palliative sedation (PS) is estimated to precede 10-18% of all deaths in Europe, although there is known to be considerable diversity in its use. Although there are national and international clinical guidelines for PS … the quality and content of guidelines vary because the terminology and concepts lack consensus, and they are infrequently used, The practice of PS, in particular when it is applied as continuous deep sedation until death, raises important and controversial issues because some people have suggested that it may result in life-shortening effects and potentially result in what has been described as "slow" euthanasia, although the empirical evidence does not support this contention. Also, the use of PS for patients with mainly existential suffering remains controversial. The practice of PS, therefore, raises many practical and ethical dilemmas for clinicians and is often poorly understood by patients and families. Witnessing the "intolerable" suffering of others is distressing, both for family members and the clinical team. There is a lack of clarity in the assessment and management of refractory symptoms, to determine the right moment to start PS, the influence of different cultural, religious, and social norms, and how health professionals, patients, and families understand these (decision) processes and treatment options. **Full text:** http://bit.ly/2wAOZz3

Palliative
Sedation

EU Horizon 2020
Research Project:
http://bit.ly/2SRcdcS

Noted in Media Watch 30 December 2019 (#646, p.7):

- *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

Noted in Media Watch 9 December 2019 (#643, p.7):

- *AUSTRALIAN JOURNAL OF GENERAL PRACTICE*, 2019;48(12). **'Palliative sedation: A safety net for the relief of refractory and intolerable symptoms at the end of life.'** Primary care doctors may be involved in multidisciplinary team meetings discussing palliative sedation (PS) for their patients in a hospital setting. Alternatively, family members whose loved ones have required PS may need to be followed up and monitored for psychological and moral distress, which is why it is important for general practitioners to be aware of this therapy. PS is complex. There is currently no Australian PS framework for primary care doctors to apply in different clinical settings (e.g., home, residential homes and rural/remote areas). **Full text:** http://bit.ly/2rQgm5U

N.B. Additional articles on palliative (or terminal) sedation noted in 28 October 2019 issue of Media Watch (#637, p.11).

Palliative care implementation in long-term care facilities: European Association for Palliative Care White Paper

JOURNAL OF POST ACUTE & LONG-TERM CARE MEDICINE | Online – 27 February 2020 – This is the first study that the authors are aware of that has formulated recommendations on strategies for implementation of palliative care (PC) interventions in long-term care facilities (LTCFs) based on international research with experts. The recommendations aim to guide how PC can be introduced, embedded, and sustained in LTCFs. Eighteen international experts from 15 countries participated in a 1-day face-to-face Transparent Expert Consultation (TEC) workshop... The TEC study offers a framework of recommendations at each level in which strategies can be implemented and has outlined the processes involved, although the authors acknowledge that change is unlikely to be linear. Building upon a scoping review, which focused predominantly upon micro and meso domains, the TEC processes have expanded the focus to highlight strategies at the macro level, including national level policies, LTCF standards, and ultimately the healthcare systems and geopolitical contexts in which they operate. Recommendations such as establishing minimum general PC competencies for LTCF staff and ensuring relevant regulatory frameworks address the provision of PC in LTCFs require the support of macro-level factors, which may be outside the scope of specific interventions being delivered. The highly ranked recommendations reflect all domains of activity, although more focused on meso-level and micro-level processes. Creating a culture of ongoing development for staff requires a commitment to educational opportunities and resource allocation, in terms of staff time and payment. In addition, creating a culture in which staff feel comfortable reflecting on current practice and addressing areas for improvement requires explicit support from senior managers. These are largely dependent on the LTCF leaders to facilitate an organizational culture supporting change. The results indicate that meso-level activities are central to creating a culture in which interventions can be implemented and sustained. **Full text:** http://bit.ly/2wicpcg

Related:

- *AGE & AGEING* | Online – 24 February 2020 – **'Care home residents who die in hospital: Exploring factors, processes and experiences.'** The authors explored the factors that influence hospital admission of care home residents who then died in hospital. Most admissions occurred out-of-hours (69%) and most were due to a sudden event or acute change in clinical condition (72%). Length of stay in hospital before death was short, with 42% of deaths occurring within 3 days. Anticipatory Care Planning (ACP) regarding hospital admission was documented in 44%. Care home staff wanted to care for residents who were dying; however, uncertain trajectories of decline, acute events, challenges of ACP, relationship with family and lack of external support impeded this. **Abstract:** http://bit.ly/2vbRp72

- *CANADIAN NURSE* | Online – 24 February 2019 – **'Embedding palliative approaches to care in long-term care.'** According to the 2016 Canadian Census, 6.8% of the population aged 65 years and older were living in long-term care (LTC); this figure jumps to 30.0% among Canadians aged 85 years and older, with over 90% of those admitted having a life-limiting diagnosis. LTC staff are ideally positioned to facilitate meaningful, timely conversations on advance directives and end-of-life care with residents and their families, but need the competence, support, and tools to do this. A cultural shift in how we talk about death and dying is required to facilitate acceptance and understanding of what palliative care is and how it can improve people's lives. **Full text:** http://bit.ly/2wNM2vh

  JOURNAL OF PALLIATIVE CARE | Online – 27 February 2020 – **'Transitioning to life in a nursing home: The potential role of palliative care.'** This study provides insights into the experiences of transitioning to a nursing home (NH) from the perspectives of palliative care (PC) eligible residents and their families. These data describe how PC eligible residents and their families experienced disempowerment as they perceived being left out of decisions to go to a NH, loss of autonomy once at the NH, dealt with the realization that they would not be going home, and described perceived barriers to going home. The inclusive and person-centered model of care that PC provides naturally empowers residents and family members. **Abstract (w. list of references):** http://bit.ly/32E0u50

N.B. Additional articles on hospice and PC in long-term care noted in 24 February 2020 issue of Media Watch (#654, p.14).

Power and perils of prediction in palliative care

THE LANCET, 2020;395(10225):680-681. As artificial intelligence (AI) spreads across clinical specialties, its potential to revolutionise healthcare at the individual and population levels has placed it alongside genomics as one of the frontiers in medicine. The promise that AI could help health systems and clinicians optimise patient care in core domains of diagnosis, prognosis, and treatment drives widespread interest and investment. Palliative care (PC) dedicates itself to improving the quality of life (QoL) and experiences of people dealing with serious illness. Interprofessional teams work to alleviate symptoms, facilitate communication, prioritise psychological care, and mitigate distress. At its core, PC is both motivated and challenged by irreducible uncertainty and contextual variability. Machine learning technologies can be useful in PC, especially as clinicians and health systems seek to allocate and improve access to scarce PC resources. The potential of machine learning models in PC is their capacity to rapidly analyse data from various sources to predict who is likely to progress to unacceptable functional dependence or even die. Such predictions can signal who might need additional support, such as targeted communication or a PC consult. Appropriately timed introduction of PC services improves outcomes such as QoL, patient and caregiver satisfaction, and healthcare spending efficiency. Figuring out who should get specialty PC and when is one of the field's most pressing questions. **Full text:** http://bit.ly/2IgcUGV

Noted in Media Watch 16 December 2019 (#644, p.3):

- *HEALTH IT ANALYTICS* | Online – 9 December 2019 – **'Machine learning could improve end-of-life communication.'** Machine learning tools could analyze conversations between providers and patients about palliative care (PC), leading to improved communication around serious illness and end-of-life treatment, according to a study conducted at the University of Vermont's (UVM) Conversation Lab.[1] Researchers used machine learning techniques to analyze 354 transcripts of PC conversations collected by the Palliative Care Communication Research Initiative. Conversations tended to progress from talking about the past to talking about the future, and from happier to sadder sentiments. **Full text:** http://bit.ly/36ngs41

    1. 'Story arcs in serious illness: Natural language processing features of palliative care conversations,' *Patient Education & Counseling*, published online 9 December 2019: **Abstract:** http://bit.ly/2RAyb3E

Health-related quality of life in patients with advanced cancer who express a wish to hasten death: A comparative study

PALLIATIVE MEDICINE | Online – 27 February 2020 – Some evidence suggests the wish to hasten death is related to poor health-related quality of life (QoL). Deficits in perceived dignity and self-efficacy are risk factors for wish to hasten death that also impact health-related QoL. 153 adult patients with advanced cancer were assessed for wish to hasten death using the Desire for Death Rating Scale. Patients with a wish to hasten death had worse emotional functioning, greater perceived loss of dignity, and lower self-efficacy. There was no difference in most physical symptoms. Perceived overall health-related QoL was significantly worse for those with a clinically relevant wish to hasten death and marginally worse for the case group than the control group. Patients with wish to hasten death showed lower perceived dignity, self-efficacy and emotional QoL than patients without wish to hasten death without necessarily perceiving worse physical symptoms. **Abstract (w. list of references):** http://bit.ly/3853kB9

Noted in Media Watch 27 May 2019 (#615, p.8):

- *BIOETHICS*, 2019;33(4):439-447. **'Self-perceived burden to others as a moral emotion in wishes to die. A conceptual analysis.'** Patients at the end of their life who express a wish to die sometimes explain their wish as the desire not to be a burden to others. This feeling needs to be investigated as an emotion with an intrinsically dialogical structure. Two key meanings of the feeling of being a burden to others as a reason for a wish to die are identified. First, it is an existential suffering insofar as it contains the perception of a plight so desperate that it can only be relieved by the end of the patient's existence. Second, it is an empathic concern that implies caring about those who bear the burden of caring for the person at the end of their life. **Abstract:** http://bit.ly/2wrq2Db

Cont.

N.B. The focus of this special issue of *Bioethics* is on "being a burden to others and wishes to die." Journal contents page: http://bit.ly/2W22ljH. Additional articles on wishes to hasten death noted in 4 February 2019 issue of Media Watch (#600, p.15).

Towards person-centred quality care for children with life-limiting and life-threatening illness: Self-reported symptoms, concerns and priority outcomes from a multi-country qualitative study

PALLIATIVE MEDICINE | Online – 21 February 2020 – This cross-sectional qualitative study in Kenya, Namibia, South Africa and Uganda bridges an important knowledge gap regarding symptoms, concerns and outcomes that matter to children living with life-limiting conditions and their families and informs service development and evaluation. 120 interviews were conducted with children with life-limiting conditions, and where self-report was not possible, caregivers of children were included. Conditions included advanced HIV (22%), cancer (19%), heart disease (16%) endocrine, blood and immune disorders (13%), neurological conditions (12%), sickle cell anaemia (10%) and renal disease (8%). Outcomes identified included physical concerns: pain and symptom distress; psycho-social concerns – family and social relationships, ability to engage with age-appropriate activities (e.g., play, school attendance); existential concerns – worry about death, and loss of ambitions; healthcare quality – child- and adolescent-friendly services. Priority psycho-social concerns and health service factors varied by age. **Abstract (w. list of references):** http://bit.ly/32qA6v7

Support interventions for families of people with terminal cancer in palliative care

PALLIATIVE & SUPPORTIVE CARE | Online – 26 February 2020 – The terminal phase of cancer represents a major crisis for the family system. Regardless of the caregiving role they undertake, family members are forced to address multiple impacts when facing the approaching death of their terminally ill loved one. International guidelines recognize the importance of integrating the family into a care plan. However, more needs to be known about how to deliver optimal family support. The purpose of this study is to review the current state of the art in family/caregiver-focused interventions of people with terminal cancer in palliative care (PC). Nine interventions were found in the systematic reviews of literature and meta-analysis. These family/caregiver-focused interventions were then thoroughly and critically analyzed. Despite the heterogeneity with regard to their characteristics, the interventions commonly focused on caregiving matters, were brief in duration, and delivered by non-mental health experts. The efficacy of such interventions was seen as modest. Family/caregiver-focused interventions in PC remain a matter of concern and more research is needed to identify adequate and effective ways of helping families that face the crisis of terminal illness in the system. **Abstract (w. list of references):** http://bit.ly/2Pt5SlQ

New directions to advance family caregiving research

THE GERONTOLOGIST | Online – 14 February 2020 – A new supplemental issue of the journal *The Gerontologist* from the Gerontological Society of America shares 10 research priorities to better support the needs of family caregivers. The contents are the result of the 'Research Priorities in Caregiving Summit,' an expert gathering hosted in March 2018 by the Family Caregiving Institute (FCI) at the University of California. Attendees included representatives from service agencies, funding organizations, and academia. **Full text:** http://bit.ly/32rwgly

N.B. Journal contents page: http://bit.ly/3cdJLJQ

Related:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 24 February 2020 – **'Effect of instrumental support on distress among family caregivers: Findings from a nationally representative study.'** A priority focus on palliative and supportive care is helping the 43.5 million caregivers who care for individuals with serious illness. Lacking support may lead to caregiver distress and poorer care delivery to patients with serious illness. The authors examined the potential of instrumental support ... to mitigate distress among caregivers. Poor instrumental support is associated with high distress among caregivers, suggesting the need for palliative and supportive care interventions to help caregivers leverage instrumental support. **Abstract (w. list of references):** http://bit.ly/2w3NSYu

Assessing patients' preferences for breaking bad news according to the SPIKES-Protocol: The MABBAN Scale

PATIENT EDUCATION & COUNSELING | Online – 27 February 2020 – Quality of breaking bad news can seriously affect the course of disease. A frequently applied guideline is the SPIKES-Protocol that have been designed from the physician's perspective. Little is known about patients' preferences in breaking bad news. The Marburg Breaking Bad News Scale (MABBAN) was developed and administered to 336 cancer patients. The novel questionnaire supported the six SPIKES-components of breaking bad news: Setting, Perception, Invitation, Knowledge, Emotions, and Strategy. Depending on clinical and demographic variables different components were rated as important. Using SPIKES as a framework can optimize breaking bad news conversations but it seems important to emphasize the individual preferences beyond the six steps and tailor the communication process to the individual. **Abstract:** http://bit.ly/2wgQmmh

Making end-of-life and palliative care viable in India: A blueprint for action

NATIONAL MEDICAL JOURNAL OF INDIA | Online – 18 February 2020 – India is distinctly not a country to die in! Our failure begins with our underfunded public health system. However, both in the U.K. and our own Kerala, it has become obvious that public funding is far less effective than voluntary action and philanthropy. Governments' involvement, however, is necessary to enable, mandate and support these efforts by legislative or executive action or both. There is scope for private healthcare as well, as in the U.S., where these services, including home or institutional hospice care, are usually funded by medical insurance. How well a healthcare system manages death seems to depend on some rather simple, low-cost and low-technology factors. Probably, the most important of these is public awareness and the naturalization of death in our daily discourse. The next issue is the availability of morphine and other opioids for the pain and distress that so many suffer from in their last days. This is because of worries about potential misuse. WHO has helped evolve systems that have been put in place by other developing countries such as Mongolia to make these vital but inexpensive drugs available to whoever genuinely needs them. Not so in India where the lack of a legal framework affects the domain of end-of-life care (EoLC). In March 2018, the Supreme Court of India finally recognized autonomy of healthcare choices as a constitutional right. This includes the right to limit medical care at the end of life and the validity of living wills. As of now, a doctor's duty is still perceived to be to make every attempt to save life even if it means disregarding the patient's clear instructions to allow natural death. Most Indian healthcare professionals are never trained to recognize and respond to EoLC needs or to provide even basic palliative care. This lack of a systematic approach or of training is seen at all levels: doctors, nurses, counsellors, administrators, etc. Few hospitals invest in these inexpensive services, which could save costs all around while improving the quality of life at the end. **Full text:** http://bit.ly/2SS47kw

Extract from *National Medical Journal of India* article

This field requires skill-sets and attitudes that are somewhat distinct from the rest of medicine. There is a high degree of voluntarism and altruistic behaviour in personnel who devote their professional careers to end-of-life and palliative care. Philanthropic and non-governmental organizations can and do provide a yeoman service. Maintaining professional standards and ethics can be a major challenge especially as patients are among the most vulnerable in our society. There is a considerable fit and overlap between these services and those that will need to be provided to senior citizens. Except for physician training for which some facilities do exist, for the rest, organized training programmes will largely have to be set up from scratch.

N.B. Additional articles on end-of-life and palliative care in India noted in 13 January and 3 February 2020 issues of Media Watch (#648, p.10, and #651, pp.7-8, respectively).

Five strategies to expand palliative care in safety-net populations

NEJM CATALYST INNOVATIONS IN CARE DELIVERY, 2020;1(2). Clinicians need to re-examine how they care for safety-net populations, especially when such vulnerable patients are living with life-limiting conditions. The authors offer five strategies to develop robust palliative care programs aimed at improving care for these populations: 1) Utilizing lay health workers; 2) Addressing gaps in care and setting goals of care; 3) Creating specialized interventions; 4) Shaping the interdisciplinary team for resilience support; and, 5) Addressing opioids. **Abstract:** http://bit.ly/2SUhXmj

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMC NURSING* | Online – 17 February 2020 – **'The rocks and hard places of medical assistance in dying (MAiD): A qualitative study of nursing practice in the context of legislated assisted death.'** Findings from this study describe the impact of a legislated approach to assisted death on Canadian nursing practice and nurses' experience. Such findings illustrate the proverbial rock and hard place in which nurses' have obligations in relation to the MAiD legislation but find themselves in the complex situation of trying to negotiate best practices with variable support. Nurses in this study described a high degree of variability in policies and procedures, system processes, and team support across Canadian jurisdictions. They further described the importance of teamwork in facilitating such an impactful event. Finally, they described the complexity of facilitating a patient-centered death within a system that was not always well structured to support their efforts. These factors influenced their experiences with assisted death, and their willingness to take part, beyond any considerations of conscientious objection. **Full text:** http://bit.ly/2I9Bb1j

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 February 2020 – **'Suicide attempt following determination of ineligibility for assisted death: A case series.'** Medical assistance in dying (MAiD) and similar right-to-die laws are becoming increasingly common in jurisdictions across North America and elsewhere. To be eligible for MAiD in Canada, requesters must have a serious illness, intolerable suffering, and a reasonably foreseeable natural death. They must also undergo two assessments to confirm eligibility. While a growing body of literature now exists to help clinicians understand and support patients around requests for assisted death, a dearth of literature exists on how best to support those patients who are deemed ineligible. The authors report on a case series of three patients who attempted suicide after being found ineligible for MAiD. Two patients were ineligible because they did not appear to have reasonably foreseeable natural death. The third patient was ineligible due to concerns around decisional capacity. All three cases had previous diagnoses of depressive disorders and mild cognitive impairment, and two had histories of suicide attempts. In at-risk patients, the authors speculate that the period of time surrounding a finding of MAiD ineligibility may represent a period of particular vulnerability. Clinicians must be vigilant and prepared for the possibility of heightened risk, including risk of self-harm, following a finding of ineligibility for assisted death. **Abstract (w. link to references):** http://bit.ly/2HUsk3g

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

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