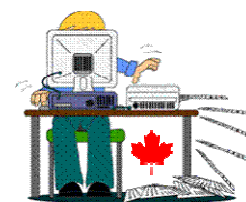


Media Watch...

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

Each [freestanding inpatient hospice center] is an oasis where people with complicated, intractable distress benefit from technically sophisticated treatments for their symptoms that are delivered with tenderness in welcoming, home-like settings. Comfort reliably results. People's intimacy is respected; their dignity preserved.

'Hopewell House hospice has closed. You should care about that,' (p.2), in *Stat News*.

Canada

Palliative care patients, doctors, caregivers in Quebec desperate for more home care services

QUEBEC | Global TV News (Montreal) – 19 November 2019 – A fight is brewing between Quebec's general practitioners and their union, leaving palliative care (PC) patients stuck in the middle. The Federation des médecins omnipraticiens du Quebec (FMOQ) and the province signed an agreement in March to create 68 palliative home care units in the province. But nine months later, there is only one unit on the ground, meaning many Quebecers are being denied the right to die at home. "The majority of patients in PC wish to stay at home and actually, in the Quebec province, they are robbed from this right," said Dr. Genevieve Dechène, who runs the province's only palliative home care unit in Verdun. The Quebec coalition for access to PC blames the FMOQ for blocking the development of the medical teams at home. "This is totally unacceptable," said Dechène, who claims the union is putting physicians' financial interests first. A group of physicians, patients and caregivers teamed up at a [recent] news conference to speak out against the FMOQ, but its president believes their grievances should be redirected to the health minister. "To say that the federation is blocking the recommendation of new teams, it's

completely false, it's not true," said FMOQ president Dr. Louis Godin, who claims he's been waiting for the minister to modify the agreement for nine months. <http://bit.ly/2pE7Kia>

Specialist Publications

“Nothing about us, without us.”: How community-based participatory research methods were adapted in an Indigenous end-of-life study using previously collected data (p.10), in *Canadian Journal on Aging*.

'Palliative sedation and medical assistance in dying: Distinctly different or simply semantics?' (p.17), in *Nursing Inquiry*.

'Determination of competency for high-gravity life-death decision-making' (p.17), in *Psychological Injury & Law*.

Advance care planning in Canada: A Pan-Canadian Framework

CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION | Online – 18 November 2019 – The Framework focuses on four interwoven activities: 1) Extend the partnership network – engage other sectors, such as law, life/financial planning and social services, and other people-centered health initiatives, in supporting and encouraging advance care planning (ACP); 2) Build supportive systems – remove legal, health and other systemic barriers to ACP, and develop effective ways for people to record and share their ACP wishes and ensure the health care system respects those wishes; 3) Engage and educate all stakeholders – normalize ACP and make it part of life planning, develop culturally respectful and safe strategies to reach underserved communities, and provide training and support for service providers and other champions of ACP; and, 4) Measure impact – establish targets and key performance indicators for ACP, track progress and use the results to drive change and quality improvement. **Download/view at:** <http://bit.ly/2KFVVGUS>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *The Ottawa Citizen* – 20 November 2019 – ‘**Is a lack of affordable care options forcing some to choose medically assisted death?**’ There has been a flurry of discourse in the media regarding ways to make medically assisted death more accessible for Canadians, including reports on the Quebec ruling to overturn the criterion that one’s death must be “reasonably foreseeable” and the Alzheimer Society of Canada position statement supporting advance requests for medical assistance in dying (MAiD). Notably absent from the discussion is how to address the reasons compelling Canadians to choose MAiD. <http://bit.ly/2rYWcGS>

U.S.A.

Pennsylvania family caregivers providing billions in services

PENNSYLVANIA | Public News Service – 20 November 2019 – One-point-three-billion-hours [valued at more than \$18 billion] – that’s how much unpaid time family caregivers (FCs) in Pennsylvania devoted to helping aging family members and friends remain in their homes in 2017, according to a new report.¹ A paid family leave bill soon to be introduced in the [State’s] General Assembly would give FCs paid time off to help care for a child, a spouse or an aging parent. <http://bit.ly/2s340HQ>

Specialist Publications

‘End-of-life care during the national opioid crises: A national survey of hospice providers,’ (p.10), in *Innovation in Aging*.

1. ‘Valuing the Invaluable 2019 Update: Charting a Path Forward,’ Public Policy Institute, American Association of Retired Persons, November 2019. **Download/view at:** <http://bit.ly/337bHJE>

Hopewell House hospice has closed. You should care about that

OREGON | *Stat News* (Boston, Massachusetts) – 19 November 2019 – Hopewell House, an inpatient hospice facility in Portland, Oregon has closed its doors. Should anyone care beyond the families of the thousands of people who would have died badly had it not been for Hopewell House? ...everyone should care, because its closing highlights a chasm in the continuum of health services needed to prevent people from suffering needlessly before dying. Only a handful of freestanding inpatient hospice centers like Hopewell operate across the US. Each is an oasis where people with complicated, intractable distress benefit from technically sophisticated treatments for their symptoms that are delivered with tenderness in welcoming, home-like settings. Comfort reliably results. People’s intimacy is respected; their dignity preserved. By the time Hopewell House closed its doors on 30 September, about 10,000 people had

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died there and another 9,000 or so had had their symptoms brought under control and returned home under continued hospice care. What's forcing intensive hospice care facilities like Hopewell House to close is inadequate reimbursement for the services they provide. Overly restrictive Medicare and Medicaid regulations force programs to leave existing licensed hospice beds unfilled for fear of being fined for transgressing strict eligibility rules. From 2012 to 2017, inpatient hospice use dropped nearly 30% at Hopewell House and 15% across Oregon, decreases that are consistent with national trends. For-profit companies now dominate America's hospice "industry" and, for the regulatory and financial reasons described, rarely open or operate hospice inpatient units. <http://bit.ly/2KPFXCT>

Noted in Media Watch 23 September 2019 (#632, p.14):

- **PROGRESS IN PALLIATIVE CARE** | Online – 16 September 2019 – ‘**Future-proofing the palliative care workforce: Why wait for the future?**’ Careful consideration of workforce issues is not new in palliative care (PC). Indeed, calls for workforce development and future workforce planning to address shortages have been evident within the international literature for quite some time. However, there now appears to be a growing urgency. Studies conducted by the American Academy of Hospice & Palliative Medicine's Workforce Task Force have pointed towards an impending crisis in the form of a “workforce valley” associated with factors such as burnout, intention to leave PC, retirement age demographics, and limitations in specialist training.¹ **First page view:** <http://bit.ly/2krYIC9>

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>

Noted in Media Watch 15 April 2019 (#610, p.2):

HOSPICE NEWS | Online – 10 April 2019 – ‘**Non-profit hospices fight to compete with for-profit chains.**’ Non-profit hospices have been bleeding market share for several years – but are not going gentle into that good night. Rather, many non-profits are adapting to compete with large for-profit providers that are entering the space in greater numbers. In the 1980s and 1990s non-profits provided virtually all hospice care in the U.S., but the balance has shifted. In 2016, 67% of Medicare-certified hospices were for-profit, and only 20% were non-profits... For-profit hospices accounted for 100% of new providers established during 2017, the Medicare Payment Advisory Commission reported in March. <http://bit.ly/2FZXG72>

International

Taiwan allows patients of 11 rare diseases decision-making power

TAIWAN | Focus Taiwan (Taipei) – 22 November 2019 – Taiwan's Ministry of Health & Welfare ... included 11 rare diseases in the clinical conditions under which the Patient Right to Autonomy Act is applicable, giving those suffering from such illnesses the right to decide whether to continue life support or other treatment. The Act, the first of its kind in Asia, came into effect in January. It offers people the right to decide in advance what medical treatment or health care they accept when they are terminally ill, in an irreversible coma, in a permanent vegetative state, suffering from severe dementia, or in other disease conditions that the authorities determine are unbearable or incurable. Such patients are

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Specialist Publications

‘**A worldwide bibliometric analysis of publications on advance care planning in the past three decades**’ (p.7), in *American Journal of Hospice & Palliative Medicine*.

‘**Provision of palliative and end-of-life care in New Zealand residential aged care facilities: General practitioners’ perspectives**’ (p.7), in *Australian Journal of Primary Health*.

‘**Mapping levels of palliative care development in 198 countries: The situation in 2017**’ (p.12), in *Journal of Pain & Symptom Management*.

entitled to the right to terminate life-sustaining treatment, as well as artificial nutrition and hydration, under the Act. As part of its implementation of the Act, the ministry included 11 rare diseases in the definition of the disease conditions determined to be unbearable or incurable, after a series of expert meetings over the past year. The diseases include multiple system atrophy, Duchenne muscular dystrophy, hereditary epidermolysis bullosa, Huntington disease, and limb-girdle muscular dystrophy. Other diseases added to the list are: nemaline myopathy, spinocerebellar ataxia, spinal muscular atrophy, amyotrophic lateral sclerosis, cystic fibrosis, and primary pulmonary hypertension. <http://bit.ly/2OEMS2D>

Older people dying for want of social care at rate of three an hour

U.K. (England) | *The Guardian* (London) – 20 November 2019 – At least 74,000 older people in England have died, or will die, waiting for care between the 2017 and 2019 general elections. A total of 81 older people are dying every day, equating to about three an hour, research by Age UK has found.¹ In the 18 months between the last election and the forthcoming one, 1,725,000 unanswered calls for help for care and support will have been made by older people. This, said the charity, was the equivalent of 2,000 futile appeals a day, or 78 an hour. Age UK's director, Caroline Abrahams, said: "This huge number of requests for help did not lead to any support actually being given for three main

reasons: because the older people died or will die before services were provided, because of a decision that they did not meet the eligibility criteria as interpreted by their local authority, or because their local authority signposted them to some other kind of help than a care service." <http://bit.ly/2XCoEKB>

Specialist Publications

'Austerity in the U.K. and poor health: Were deaths directly affected?' (p.9), in *British Journal of Healthcare Management*.

1. 'In England 74,000 older people have died or will die waiting for care between the 2017 and 2019 General Elections,' Age UK, November 2019. <http://bit.ly/2KM2FeQ>

One in four people in Wales denied access to end-of-life care

U.K. (Wales) | Deeside.com (Flintshire) – 20 November 2019 – North Wales Assembly Member Mark Isherwood, who Chairs the Assembly's Cross-Party Group on Hospices & Palliative Care, has called on the Welsh Government to take action to help radically improve access to hospice and palliative care (PC) for everyone across Wales. Mr. Isherwood said that while approximately 23,000 people in Wales have a PC need at any one time, including over 1,000 children, around 1 in 4 – approximately 6,000 people – don't get access to the end-of-life care they need: "As the Cross Party Group on Hospices & Palliative Care's report ... found, despite some progress in widening access to hospice and PC in Wales, there remains significant unmet need and under-met need."¹ Mr. Isherwood also expressed concern that hospices are experiencing a number of challenges which impact on their ability to provide sufficient support services, including a lack of statutory Welsh Government funding, an out-of-date funding formula leading to a "postcode lottery" of services, and unmet need caused by a lack of specialist PC staff. "Government funding of children's hospices in Wales as a percentage of its charitable expenditure is lower than in England and Scotland. In Wales, children's hospices received 12% of their expenditure from government funding last year, compared with 21% in England and 53% in Scotland. <http://bit.ly/35qtkGb>

1. 'Inequalities in access to hospice and palliative care,' Cross-Party Group on Hospices & Palliative Care, National Assembly of Wales, July 2018. [Noted in 16 July 2018 issue of Media Watch (#572, p.4)] **Download/view at Hospice UK:** <http://bit.ly/35nDg2Y>



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Nursing crisis forces closure of Butterwick Hospice unit for second time in weeks

U.K. (England) | *Teeside Live* (Middleborough) – 19 November 2019 – The Butterwick Hospice is temporarily closing its children’s unit for the second time in a few weeks because of a “deepening national nursing crisis.” In September, the Stockton service announced it was closing its children’s section until 21 October because staffing levels were too low to offer “safe care.” But now, having reopened for just a few weeks, and with a new team in place, the unit is closing again “in the interests of patient safety” – and won’t reopen until early 2020. The news was announced in a statement from Butterwick Hospice Care, saying the decision was “beyond Butterwick’s control.” <http://bit.ly/2OwJ9V0>

Noted in Media Watch 21 October 2019 (#636, p.5):

- U.K. | *The Daily Mirror* (London) – 12 October 2019 – ‘**U.K. in end-of-life care crisis as 100,000 people die each year without dignity.**’ Campaigners say the National Health Service is battling a shortage of 3,500 nurses needed to support people dying at home. Funding problems, meanwhile, forced the closure of a string of hospices which comfort and care for the terminally ill. And around 80% of hospices which rely on charity will fall into the red next year...¹ An extra £25 million funding was announced by the Government in August – a “drop in the ocean,” said Dr. Amy Proffitt [of the Association of Palliative Medicine].² The average adults hospice receives 30% of funds from health budgets and the rest through charities, donation and fundraisers, according to Hospice UK.³ <http://bit.ly/31bGvlz>
 1. ‘Eight in ten charitable hospices planning a deficit budget this financial year,’ Hospice UK, September 2019. [Noted in 14 October 2019 issue of Media Watch (#635, p.7)] <http://bit.ly/2obgnA9>
 2. ‘£25 million for hospices won’t go far,’ *British Medical Journal*, 18 September 2019. [Noted in 23 September 2019 issue of Media Watch (#632, p.8)] Full text: <http://bit.ly/2lW27cS>
 3. ‘U.K. hospices face funding crisis as one in three forced to cut end-of-life services,’ ITV News, 7 May 2019. [Noted in 20 May 2019 issue of Media Watch (#614, p.6)] <http://bit.ly/3071bSA>

Noted in Media Watch 28 October 2019 (#637):

- U.K. (England) | Together for Short Lives – 20 October 2019 – ‘**Shortage of nurses and doctors in England hitting care for seriously ill children.**’ ‘A workforce in crisis: Children’s palliative care in 2019’ shows a children’s palliative care (PC) workforce at breaking point: 1) There are just 15 children’s PC consultants in the UK; 2) The nursing vacancy rate in children’s hospices is growing, with posts increasingly difficult to fill; 3) There are too few skilled children’s nurses to fill vacant posts in the National Health Service (NHS) and children’s hospices; 4) There are too few community children’s nurses employed by the NHS; and, 5) There are shortages among other important health and care professionals. **Download/view report at:** <http://bit.ly/33RWkG6>

The reality of death is too vast and too confounding to be described in just one word

U.K. (England, Northern Ireland, Scotland & Wales) | *The Telegraph* (London) – 19 November 2019 – I heard it argued recently, on a podcast about grief, that saying “My father died” is insufficiently honest. Instead, one should say “My father is dead,” to better recognise that death is an ongoing condition rather than a one-off tragedy. This struck me as both true and uncomfortably strict. There is, at the moment, a craze for speaking bluntly about death. It began, as so many fashionable ideas do, as a necessary reaction to the *status quo*. Modern death is so discreetly done, overseen by professionals in hospitals and funeral homes, that it often feels weirdly invisible. Using delicate or obfuscating language is thought to reinforce the sense of taboo. The charity Marie Curie has just released a list of the 50 most popular British euphemisms for death.¹ <http://bit.ly/2KR0dnF>

1. ‘Poll [of nearly 8,000 people] reveals over 50 different euphemisms for death,’ Marie Curie, November 2019. <http://bit.ly/32Xul17>



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

Doctors question ability of patients to make complex medical decisions in advance

AUSTRALIA | *Naracoorte Herald* (Naracoorte, South Australia) – 18 November 2019 – Australian doctors sometimes ignore advance care directives (ACDs) not believing in the ability of non-medically trained patients to make complex medical decisions for themselves in advance, according to a new study.¹ Even though ACDs are legally binding documents some doctors struggle to comply with patient choices and the study findings challenge the widely held assumption that personal autonomy and choice trumps all in medical treatment decision making. The study ... uncovers the complexity and difficulty faced by doctors when enacting ACDs and the deep conflict in weighing up whether to follow a patient's directive. The research presented 21 doctors from a Melbourne hospital with real-life scenarios to explore how doctors use ACDs to guide medical treatment decision making. The study found that overall, doctors appeared more motivated to act in what they considered to be the patient's best interests rather than upholding the individual's autonomy of following a legally-binding directive. The doctors were most likely to rely on their own judgement and override patient

choices when: 1) ACDs were not current, were too vague or incoherent; 2) ACDs were not easily accessible at the point of care; 3) They encounter family opposition' and, 4) Faced with a patient with a condition the doctor deemed to be potentially reversible. The study found that doctors sometimes doubted the validity of ACDs questioning how well equipped non-medically trained people were to make nuanced and complex medical decisions and whether a person could make such important decisions and informed choices in advance. <http://bit.ly/3718z0h>

Specialist Publications

'Voluntary stopping of eating and drinking in advance directives for adults with late-stage dementia' (p.7), in *Australasian Journal on Ageing*.

'The advance care planning nurse facilitator: Describing the role and identifying factors associated with successful implementation' (this page), in *Australian Journal of Primary Health*.

1. 'Doctors' perspectives on adhering to advance care directives when making medical decisions for patients: An Australian interview study,' *BMJ Open*, published online 31 October 2019. [Noted in 4 November 2019 issue of *Media Watch* (#638, p.13)] **Abstract:** <http://bit.ly/2PzCAmB>

Specialist Publications

The advance care planning nurse facilitator: Describing the role and identifying factors associated with successful implementation

AUSTRALIAN JOURNAL OF PRIMARY HEALTH | Online – 19 November 2019 – This qualitative study appraised the components of an advance care planning (ACP) facilitator intervention comprising nurse-led patient screening and ACP discussions, as well as factors associated with the successful implementation of this model in primary care and acute hospital settings across rural and metropolitan Western Australia. The study identified factors associated with successful implementation, including patient factors, health professional factors, ACP facilitator characteristics, and the optimal settings for the intervention. The primary care setting was seen as most appropriate, and time limitations were a key consideration. Factors associated with successful implementation included trusting relationships between the nurse facilitator and referring doctor, as well as opportunities for meaningful encounters with patients. This study suggests a model of ACP nurse facilitation based in primary care may be an acceptable and effective method of increasing ACP uptake. **Abstract (w. list of references):** <http://bit.ly/35ejelf>

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Would this article be of interest to a colleague?

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 November 2019 – ‘**A worldwide bibliometric analysis of publications on advance care planning in the past three decades.**’ North America, Western Europe, and Australia were the most productive regions. The top 15 countries published 95.9% of the total number of articles. The U.S. accounted for approximately three-fifths (61.0%) of all publications. When adjusted for population size, Australia had the highest number of articles per million persons (6.64), followed by The Netherlands (6.14) and Belgium (4.61). The current study revealed that research in terms of publications on ACP has rapidly increased over the past 3 decades. **Abstract:** <http://bit.ly/37tIDPY>
- *AUSTRALASIAN JOURNAL ON AGEING* | Online – 19 November 2019 – ‘**Voluntary stopping of eating and drinking in advance directives for adults with late-stage dementia.**’ There is legal uncertainty in Australia around whether an advance directive to voluntarily stop eating and drinking will be followed should the adult become incompetent. Voluntary stopping of eating and drinking should be viewed in law as a form of “treatment” that competent adults can nominate in advance directives, thereby providing dementia patients with the opportunity to choose in advance, if they wish, to end their life legally, with dignity and comfort, and in a manner that does not implicate others in criminal behaviour such as assisted suicide, acceleration of death or euthanasia. **Abstract:** <http://bit.ly/2pFxn28>

Provision of palliative and end-of-life care in New Zealand residential aged care facilities: General practitioners’ perspectives

AUSTRALIAN JOURNAL OF PRIMARY HEALTH | Online – 15 November 2019 – This exploratory study examined general practitioners’ (GPs) perspectives on delivering end-of-life care (EoLC) in the New Zealand residential aged care context. Findings examine: 1) GPs’ life experience; 2) The GP relationship with the facilities and provision of EoLC; 3) The GP interaction with families of dying residents; and, 4) GP relationship with hospice. The nature of the GP relationship with the facility influenced GP involvement in EoLC in aged care facilities with GPs not always able to direct a facility’s EoLC decisions for specific residents. GP participation in EoLC was constrained by GP time availability and the costs to the facilities for that time. GPs reported seldom using hospice services for residents, but did use the reputation (cachet) associated with hospice practices to provide an authoritative buffer for their end-of-life clinical decisions when talking with families and residents. GP training in EoLC, especially for those with dementia, was reported as *ad hoc* and done through informal mentoring between GPs. **Abstract:** <http://bit.ly/343XZsj>

Noted in Media Watch 18 November 2019 (#640, p.5):

- NEW ZEALAND | Stuff.co.nz (Auckland) – 14 November 2019 – ‘**Rest homes struggling to care for patients “admitted to die,” study finds.**’ Stretched hospitals and hospices are sending elderly, terminally ill patients to die in rest homes – but staff are struggling to cope... A Otago University, Wellington, study revealed the burden aged care facilities face when caring for patients discharged from hospitals and hospices to die.¹ In the past those patients would have been cared for in public hospitals and hospices but those facilities were under increasing pressure to free up beds for acute or urgent care, the study said. Hospitals were considered inappropriate and costly for those dying over weeks to months of incurable illness, and hospice capacity is increasingly strained. <http://bit.ly/2qRvZJQ>

1. ‘What does palliative care look like in a New Zealand aged residential care facility when patients are admitted to die?’ *New Zealand Medical Journal*, 2019; 132(1505):14-28. [Noted in 11 November 2019 issue of Media Watch (#639, p.13)] **Abstract:** <http://bit.ly/34CWcKE>

[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 nurse specialists' reflections on a palliative care educational intervention in long-term care: An inductive content analysis

BMC PALLIATIVE CARE | Online – 19 November 2019 – The overall impression of the palliative care (PC) nurse specialists [from the 20 participating long-term care (LTC) facilities] was that Supportive Hospice Aged Residential Exchange (SHARE) supports the building of a strong relationship between the hospice nurse specialists and facilities, facilitates improved communication between registered nurses and residents and registered nurses and families and alerts registered nurses to be vigilant in assessing the PC needs of their residents. Furthermore, evidence from the logs indicated that the more the PC nurse specialists interacted with LTC registered nurses and healthcare assistants, the better the knowledge base for both sides. Role modeling of difficult conversations with families may build confidence in the LTC registered nurses to begin advance care planning conversations earlier as well as improve advance care planning documentation. Barriers to SHARE implementation remain however in relation to LTC staffing levels and staff turnover. Ultimately, continued implementation of SHARE and the form of that implementation are dependent on both resourcing and the commitment of all parties involved. **Full text:** <http://bit.ly/35ooKbr>



N.B. A selection of articles on palliative and end-of-life care in LTC, from past issues of Media Watch, noted in October issue of the International Association for Hospice & Palliative Care's newsletter (scroll down to 'Media Watch: Long-Term Care') at: <http://bit.ly/2p0p68g>

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 20 November 2019 – '**Palliative care training in undergraduate medical, nursing and allied health: A survey.**' Teaching about end-of-life care (EoLC) was variable across courses and professions, which echoes previous evidence looking at medical and nursing schools, but is a novel finding across multi-professional courses. The nursing and allied health courses that contained more palliative care (PC) content were those that appeared to have ... someone with experience in PC and an interest in bringing that into the curriculum in novel and creative ways. Limited funding, shortage of expert staff and placement opportunities, and limited time during the course were key concerns, which limited inclusion of EoLC. **Full text:** <http://bit.ly/2s8Xak3>
- *JOURNAL OF CANCER EDUCATION* | Online – 20 November 2019 – “**Confessions of a reluctant caregiver” palliative educational program: The results of a survey Assessing physicians' perceptions of drama-based education for end-of-life care.** Participating physicians' understanding of and comfort with end-of-life issues increased significantly after participating in the program. Moreover, they considered the program to be more useful than didactic lectures and journal articles. The results suggest that the Confessions of a Reluctant Caregiver Palliative Educational Program is a valuable education tool for palliative care training. More research is needed to explore its utility as an option for continuing medical education. **Abstract (w. list of references):** <http://bit.ly/2D5Hobl>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 22 November 2019 – '**Feasibility of using communication coaching to teach palliative care clinicians motivational interviewing.**' Coaching palliative care (PC) clinicians is feasible and shows promise... 86% of those enrolled in this study completed all study activities including coaching sessions, audio recording encounters, and completing surveys. Of those in the intervention arm, 88% rated the intervention as helpful and 100% would recommend it to a colleague. Compared to control clinicians, intervention clinicians had higher ratings of their motivational interviewing skills post-intervention, higher objectively rated communication skills, and slightly better burnout scores. **Abstract:** <http://bit.ly/2rnhmOY>
- *MEDICAL TEACHER* | Online – 18 November 2019 – '**Providing a liminal space: Threshold concepts for learning in palliative medicine.**' Experience in palliative medicine provides a beneficial learning opportunity for doctors-in-training. There is, however, a gap in understanding which aspects of learning are most useful, which are problematic, and how learning can best be facilitated. This study addresses that gap using the “threshold concepts” framework. Threshold concepts are critical points of learning, often unique to a discipline. The learning occurs within a transitional or “liminal” space and has specific characteristics including being “troublesome” and “transformative.” Five threshold concepts were identified. **Abstract:** <http://bit.ly/2r4vH2q>

Psychological burden in family caregivers of patients with advanced cancer at initiation of specialist inpatient palliative care

BMC PALLIATIVE CARE | Online – 18 November 2019 – Family caregivers (FCs) of patients admitted to specialist inpatient palliative care (PC) suffer from high psychological distress, and relevant anxiety and depressive symptoms. This demonstrates the high need of psychological support as central part of specialist inpatient PC not only for the patients, but also for their FCs. Several socio-demographic and care-related factors are significantly associated with FCs' mental burden and should be in professional carers' focus in daily clinical practice. FCs' female gender, exhaustion and worse ratings of the patient's PC outcome seem to be associated with both moderate to severe anxiety and depressive symptoms. Further supportive or psychosocial interventions – even at an earlier stage of the disease – should be developed and evaluated to better address FCs' problems and psychosocial needs in future. Since studies underscore the co-occurrence and interdependence of FCs and patients mental burden, targeting FCs problems via such interventions might have the potential to also enhance patient's quality of life and mental well-being. However, interrelationships of mental burden in dyads of patients and their FCs also raise the question, when individual versus dyadic interventions would be most beneficial. Therefore, future research on FCs mental burden and evaluation of interventions designed to address these burden should also include assessment of the patient's psychological distress. **Full text:** <http://bit.ly/2CUvPUO>

Related

- *QUALITY HEALTH RESEARCH* | Online – 19 November 2019 – **'Development and implementation of the Family Caregiver Decision Guide.'** The sequential multiple methods study reported here was designed to address the pressing need for interventions to support family members caring for seriously ill people at home. Family was conceptualized as whoever the ill person accepts as family. Following international standards and user-centered, iterative approaches for the development of decision aids, the Guide was created and subsequently refined. To the authors knowledge, this is the first intervention for family caregivers that focuses on supporting their decision making in planning care for their family member. **Full text:** <http://bit.ly/35nDg2Y>

Austerity in the U.K. and poor health: Were deaths directly affected?

BRITISH JOURNAL OF HEALTHCARE MANAGEMENT | Online – 18 November 2019 – A dramatic increase in deaths in the U.K. since 2011 has defied actuarial forecasts. This has led some to propose a direct link between the rise in deaths and government social care austerity. However, several facts argue against this link. Firstly, age standardised mortality in the second quarter of 2019 was statistically lower than the second quarter in all years since 2001, clearly austerity is still present, but age standardised mortality has recovered. Also, deaths have increased equally across the whole of the U.K., whereas social care austerity has largely been restricted to England. English citizens who are residents outside of the U.K. also show the same trend. These effects are highly reminiscent of a recurring series of disease outbreaks of an unidentified pathogen. In addition, increases in deaths are always linked to increases in hospital admissions. This link arises since around half of a person's lifetime use of acute services is compressed into the last 6 months of life, irrespective of the age at death. This is called the nearness-to-death effect. International research is needed to understand exactly why deaths are behaving in this unique way. While austerity has created a significant problem relating to delayed discharges in hospitals and has highlighted serious problems with how end-of-life care is to be funded, it seemingly cannot be blamed for the increased mortality rate. **Abstract:** <http://bit.ly/2s9eRjt>

“Nothing about us, without us.”: How community-based participatory research methods were adapted in an Indigenous end-of-life study using previously collected data

CANADIAN JOURNAL ON AGING | Online – 20 November 2019 – Indigenous health research in Canada has a chequered past and has been identified as problematic and lacking in appropriate collaboration with Indigenous people. The ‘Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans’ (Chapter 9) describes ethical conduct of research regarding ‘First Nations, Inuit, and Métis Peoples. First Nations Ownership, Control, Access & Possession.’ Principles highlight the necessity of Indigenous engagement and governance. To ensure that the aims and activities of the research being developed are in full and meaningful partnership with Indigenous peoples and communities, community-based participatory research (CBPR) methods provide a process in which full engagement is possible. Research utilizing secondary data sets, such as routinely collected health administrative data, should no longer be excluded from this approach. The authors’ aim is to describe how their research team of academic researchers and a national Indigenous health organization adapted CBPR methods in a research project using previously collected data to examine end-of-life healthcare service delivery gaps for Indigenous people in Ontario. They describe the process of how they developed their research partnership and how grounding principles and Indigenous ways of knowing guided their work together. Through the adaptation of CBPR methods, the authors’ research partnership illustrates a process of engagement that can guide others hoping to conduct Indigenous health research using previously collected data. The authors also present a transparent research agreement negotiated equally by a national Indigenous health organization and research scientists, which can also be used as a framework for others wishing to establish similar research partnerships. Ensuring that Indigenous perspectives are central to and reflected in the research process is essential when using health administrative data. **Abstract (w. list of references):** <http://bit.ly/347QmRY>

N.B. Selected articles on palliative and end-of-life care for the Indigenous peoples of Canada noted in 11 November 2019 issue of *Media Watch* (#639, pp.1-2).

End-of-life care during the national opioid crises: A national survey of hospice providers

INNOVATION IN AGING | Online – 8 November 2019 – No national data exist on drug shortages, missing medications, opioid diversion, and opioid diversion prevention in hospice. The authors randomly selected 600 hospices to survey representatives about: 1) Care for patients/families with substance use disorder (SUD); 2) Drug shortages; 3) Instances of drug diversion; and, 4) Drug disposal practices. Half of the 371 hospices that responded were mid-sized (26-100 patients) and non-profit. Two thirds reporting that medications either “never” or “rarely” go missing. On average, there were 0.80 reported cases of confirmed diversion per agency within the past 90 days. Although a majority of hospices (78%) screen patients for SUD, only 43% screen informal caregivers. Just under half (42%) of hospices reported drug shortages over the past year. A minority (8%) of hospices stopped prescribing certain medications altogether due to concerns about diversion. 52% of hospices reported that employees are not allowed to dispose of medications after a home death. Hospice representatives estimated that, after a home death, unused opioids were left in the home 32% of the time. On average, hospices have nearly one case of opioid diversion per quarter. Hospices are experiencing medication shortages and restrictions on medication disposal. Changes are needed in policy and practice to address these challenges. **Abstract:** <http://bit.ly/37fv9Ho>



Noted in *Media Watch* 10 June 2019 (#617, p.12):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2019;22(6):612-614. ‘**That was then, this is now: Using palliative care principles to guide opioid prescribing.**’ Palliative care (PC) providers ... do not want to contribute to the growing problem of opioid misuse, overdose, and accidental death. So the question becomes how do we balance the important goal of reducing suffering with our equally compelling desire to act as responsible providers. Consensus-based PC principles may serve as a clinically useful guide to the decision-making process about whether or not to prescribe opioids. The approach using these familiar core principles is probably best illustrated by the following two patients ... and their complex pain management issues. **First page view:** <http://bit.ly/2KnWQVL>

Cont.

Noted in Media Watch 11 March 2019 (#605, p.10):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2019;21(2):E1-E4. **‘Medication safety in hospice and palliative care.’** Medication safety is a top priority, particularly during today’s opioids misuse crisis. For every one death from prescription opioids, it is estimated that there are 10 treatment admissions for abuse, 32 emergency room visits for misuse or abuse, 130 people who become dependent on opioids, and 825 people who report non-medical use of these drugs. It is the position of the Hospice & Palliative Nurses Association that medication safety is an essential aspect of hospice and palliative nursing. Hospice and palliative nurses are instrumental in public education about medication safety for patient with serious illnesses, their family, and the community. **First page view:** <http://bit.ly/2ITKvt5>

Noted in Media Watch 29 October 2018 (#587, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 October 2018 – **‘Dying on hospice in the midst of an opioid crisis: What should we do now?’** In the past year, 20.2 million Americans had a substance use disorder (SUD)... In addition, the co-existence of both a mental health and SUD is very common with the use of opioids often as a means of chemical coping. Most hospice programs do not have standardized SUD policies/guidelines in place despite the increasing concerns about substance abuse within the U.S. The goal of this article is to review the literature on this topic and offer strategies on how to manage pain in patients who have active SUD or who are at risk for developing SUD in those dying on hospice. **Abstract:** <http://bit.ly/33ZgPAY>

Prison – a place for dying? An explorative study on the perspective of professionals

JOURNAL OF CRIMINOLOGY & PENAL REFORM | Online – 7 November 2019 – The authors review the results of a qualitative pilot study on the meaning of death and dying in prison from the perspective of professionals. In future years, the penal system will increasingly be confronted with the natural death of inmates and those in security detention. Against this background, this analysis of expert interviews shows specific tension between the societal ideal of “good dying” and the restrictive conditions of incarceration. Interviewees discuss the question of how best to support dying inmates within the limitations of the prison system. **Abstract:** <http://bit.ly/37izlGL>

N.B. German language article. A compilation of selected articles, etc., on end-of-life care in the prison system noted in past issues of Media Watch can be downloaded/viewed from/at the Palliative Care Network website: <http://bit.ly/2RdegnL>

Interventions for end-of-life decision making for patients with limited English proficiency

JOURNAL OF IMMIGRANT & MINORITY HEALTH | Online – 20 November 2019 – Patients with limited English proficiency (LEP) experience disparities in end-of-life (EoL) decision making and advance care planning. Eight studies from the U.S. and Australia were included (seven studies in Spanish and one study in Greek and Italian). Interventions used trained personnel, video images, web-based programs, and written materials. Interventions were associated with increased advance directive completion and decreased preferences for some life-prolonging treatments. Few interventions exist to improve EoL care for patients with LEP. Data are limited regarding intervention effectiveness. **Abstract (w. list of references):** <http://bit.ly/2QHPC24>

N.B. Additional articles on patients with limited English proficiency in the context of end of life care noted in 19 August 2019 issue of Media Watch (#627, p.8).



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

Mapping levels of palliative care development in 198 countries: The situation in 2017

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 21 November 2019 – Palliative care (PC) “resolutions” continue to appear from global health organisations, policy makers and activists, but progress towards universal PC coverage is hugely constrained. This is the only global PC development study of its kind. The authors show that the world population is effectively split down the middle: between those who live in countries with reasonably robust systems of specialised PC delivery, and those who do not. The countries with the highest levels of PC development contain 41.8% of the world population and are concentrated in the Global North, though not exclusively, while 80% of the need for PC is in low- and middle-income countries. 53.3% of the world’s population is in countries with very limited PC development mainly in the Global South, though not exclusively. The remainder of the global population (4.8%) is located in countries that have no known known PC activity or are only at the level of capacity building, and in territories that were not included in the survey (0.1%). *The Lancet* Commission on Palliative Care & Pain Relief highlighted an “access abyss” that separates those in need of PC from available services.¹ This study reveals the fragile and moderate PC assets and service infrastructure on which the goals of the Commission will be reliant as it seeks to build greater PC capacity within mainstream provision. It is likely that diffusion of the essential package of services called for in the *Lancet* report will be very difficult to deliver without increased investment in specialised PC infrastructure, as a platform from which wider implementation can occur. **Full text:** <http://bit.ly/2s1eAin>

1. ‘Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,’ *The Lancet*, 12 October 2018. [Noted in 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** <http://bit.ly/2Ww8Cku>

A “metaphor menu” cancer patients launched by researchers

MEDICALXPRESS | Online – 18 November 2019 – The first manual of expressions describing cancer has been developed by researchers to help patients make sense of their disease. The metaphor Menu ... follows research by Lancaster University based on the views of more than 100 people involved in cancer care and analysis of more than one million words.¹ Their ongoing work recommends that doctors and the media should avoid portraying cancer as a battle because this can be disempowering for terminally-ill patients and make them feel worse. However, the researchers stress there should be no “blanket ban” on certain metaphors – patients should be encouraged to use those best suiting them. “Our study shows that metaphors are helpful when talking about cancer,” says lead author Prof. Elena Semino. “But different ones suit different people, or the same person at different times. Describing someone as a ‘fighter’ can be upsetting for some patients but empowering for others. Our menu will stimulate new creative ways of talking about cancer.” The menu is targeted at patients, family carers and doctors and offers a choice of different quotes and expressions for people at all stages of the illness. **Full text:** <http://bit.ly/2Xvkhko>

1. ‘A Metaphor Menu for people living with cancer,’ Department of Linguistics & English Language, University of Lancaster, November 2019. **Download/view report at:** <http://bit.ly/35eFG3U>

Noted in Media Watch 21 October 2019 (#636, p.2):

- *USC NEWS* (University of Southern California) | Online – 16 October 2019 – **‘When it comes to cancer, fighting words might be the wrong approach.’** When it comes to cancer and other serious diseases, we often rely on words of aggression and tenacity. Patients are “fighters,” and those who experience remission or return to good health are “survivors.” Obituaries are filled with references to people “losing their battle” with an illness or “fighting until the very end.” Researchers hypothesized aggressive language might prompt participants to be more vigilant about preventing cancer and regularly check for warning signs that they might have the disease. They found people who read the “battle” or “war” version of the story perceived cancer as difficult and painful to treat.¹ <http://bit.ly/31oWP8E>

1. ‘Battle metaphors undermine cancer treatment and prevention and do not increase vigilance,’ *Health Communication*, published online 9 September 2019. **Abstract:** <http://bit.ly/2oFwTsp>

N.B. Additional articles on the use of metaphors in relation to “combating” life-limiting or life-threatening illness, notably in cancer, noted in 27 May 2019 issue of Media Watch (#615, p.3).

Long-term care in Canada

Live until you die

NURSING LEADERSHIP, 2019;32(3). In this issue, Kaasalainen *et al* highlight key components to be included in a LTC palliative program. They suggest that further work is necessary to wholly understand palliative care (PC) requirements in LTC settings. To this end, they also report on a stakeholder engagement process which included staff, residents and their families, researchers, and decision-makers. The goal of this process was to validate the strengthening of a palliative approach to long-term care model. Clausen *et al* describe a tailored leadership development program for nurse managers in an academic health network ... aimed toward strengthening individual leadership competencies and developing a resilient nursing leadership community. Given the leadership competencies addressed through this program, one might presume that it will enhance nursing leadership in support of effective end-of-life (EoL) care. In a scoping review addressing the management of chronic diseases, Gordon *et al* examine possible approaches to reduce the burden of care. They conclude that managing complex care that meets the needs of patients and providers can be effectively delivered through nurse-led models, including advanced practice models. Given that chronic conditions inevitably lead to EoL or PC, it is obvious that we should begin advanced care planning for those with long-standing disease sooner than later. Indeed, some of the same elements Kaasalainen *et al* highlight for LTC PC (e.g., training and capacity building, client and family engagement) might be worth considering in the care of all persons with a long-term illness. The distinction between managing complex chronic disease and the need to support active dying may not always be readily apparent or progress may occur more rapidly than anticipated. **Full text:** <http://bit.ly/2CUj3Wm>

N.B. Journal contents page: <http://bit.ly/2CZ44KM>

Finding a way with words: Delphi study to develop a discussion prompt list for paediatric palliative care

PALLIATIVE MEDICINE | Online – 22 November 2019 – Effective communication is a cornerstone of quality paediatric palliative care (PC). Families report struggling, however, to know what to discuss, with whom, and when. Although question prompt lists exist for adult PC, they do not suit the unique circumstances of paediatric palliative care. Underpinned by Delphi methodology, a six-phase procedure was adopted: 1) Drafting items based on the findings of a literature review; 2) Condensing the list of items based on group discussion; 3) Refining items based on a survey of expert healthcare professionals; 4) Additional refining of items based on another survey of professionals; 5) Further refining of items based on cognitive interviews with family members; and, 6) Final review by healthcare professional and family member groups. Three participant groups were involved during various phases: 1) Members of an Australasian paediatric PC national reference group; 2) Healthcare professionals associated with a local paediatric PC service; and, 3) Family members who were users of the same local service. Through multi-phase consultation across participant groups, the draft question prompt list was refined progressively to 28 items, split across two booklets to allow end-of-life items to be provided separately, and reconceptualised as a discussion prompt list rather than a question prompt list. By involving representatives of major stakeholder groups, this study has facilitated the design of a prompt list suited to the circumstances of paediatric PC. **Abstract:** <http://bit.ly/338dEG0>



Related

- *DEATH STUDIES* | Online – 23 November 2019 – **‘New adolescent grief scales open new research possibilities: A commentary.’** The authors highlight the availability of two newly developed instruments that measure grief in adolescents. They present similarities and differences regarding their content, factor structure, and characteristics of the validated populations. Given the small body of adolescent grief instruments, these two new scales will prove to be useful instruments to enhance knowledge of grief and effectiveness of grief interventions in this population. **Abstract:** <http://bit.ly/34eHVnT>

Community knowledge of and attitudes to palliative care: A descriptive study

PALLIATIVE MEDICINE | Online – 19 November 2019 – Palliative care (PC) is predominantly accessed late in the course of an illness, despite evidence to suggest the benefits of early engagement. Strategies are required to reduce the barriers to the delivery of PC. 421 participants ... reported a median of at least three misperceptions of PC. Older age, previously undertaking a caregiving role, knowing someone who had received PC and reporting more accurate knowledge of PC significantly predicted favourable attitudes to PC. Other factors typically associated with health literacy such as tertiary education, working at a medical facility and speaking a language other than English at home were not predictive. Gaps in knowledge about PC exist in community, which may limit citizen's potential access to quality care in the event of serious illness. These results point to a role for public education programmes, which may, in turn, also shift attitudes to PC. **Abstract:** <http://bit.ly/37n6ukf>

Noted in Media Watch 11 November 2019 (#639, p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 November 2019 – ‘**Examining the knowledge, awareness, and perceptions of palliative care in the general public over time: A scoping literature review.**’ The majority of studies reported the public having poor knowledge and awareness of palliative care (PC) over the past 16 years. Top characteristics associated with increased levels of knowledge and/or awareness of PC included women, age 40+, experience with a close friend and/or relative requiring PC, and working in healthcare and/or PC. Participants commonly received information about PC from the media, having a close friend or relative requiring PC, and working in a healthcare setting. **Abstract:** <http://bit.ly/2PTjKa4>

N.B. Additional articles on lack of public awareness, knowledge about, and perceptions of palliative and end-of-life care noted in this issue of Media Watch.

A systematic review of the integration of palliative care in dementia management

PALLIATIVE & SUPPORTIVE CARE | Online – 18 November 2019 – Dementia is a progressive illness with a complex biopsychosocial constellation of symptoms faced by millions of individuals and families worldwide. Palliative care (PC) teams have specialized in symptom management and end-of-life (EoL) care for decades; however, the role of PC in dementia management is not yet well elucidated. The aim of this systematic review was to understand the impact of PC in dementia management. Four key themes were identified in this review: 1) Goals-of-care and EoL conversations; 2) Symptom management; 3) Emergency room visits; and, 4) Prescribing behavior. In each domain, PC consultation either showed benefit or was postulated to have benefit if implemented. Although the literature to support or refute thematic conclusions is not large, there was a trend toward patient care benefit across several domains. Large randomized controlled trials with longer follow-up across different settings should be undertaken to solidify the themes and trends outlined in this review. Understanding the views of healthcare providers including referral sources (i.e., general practitioners and specialists) through qualitative research could optimize PC referrals, implement PC recommendations, and improve a targeted PC education curriculum.

Abstract (w. list of references): <http://bit.ly/2Nzd4RL>

Noted in Media Watch 28 October 2019 (#637, p.8):

- *BMC PALLIATIVE CARE* | Online – 24 October 2019 – ‘**Context, mechanisms and outcomes in end-of-life care for people with advanced dementia: Family carers perspective.**’ During the advanced stages of dementia people have limited capacity and verbal communication and so open communication and trusting relationships between family, care staff and healthcare professionals become paramount in providing a coordinated approach to end-of-life care. In addition to good relationships, increased provision of resources such as Admiral Nurses, staff training and advance care planning may help to reassure family carers that their relative will have a comfortable and peaceful death in a home-like environment. **Full text:** <http://bit.ly/341f1XO>

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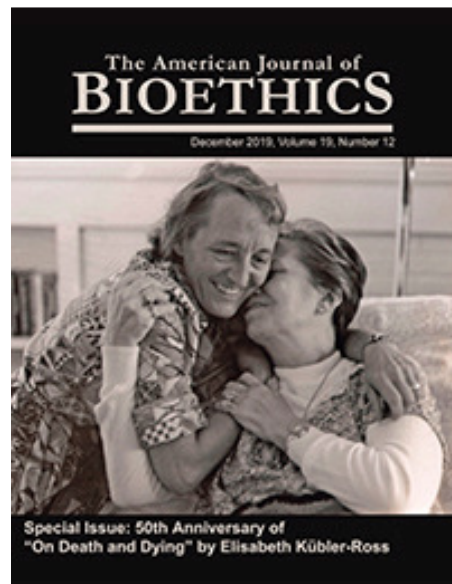
- *JOURNAL OF APPLIED GERONTOLOGY* | Online – 23 October 2019 – ‘**When death with dementia is “a memory seared in my brain”**: Caregivers’ recommendations to healthcare professionals.’ In-depth, qualitative interviews were conducted over a 12-month period, and qualitative content analysis was used to analyze the data. Three primary themes emerged: 1) Educate caregivers; 2) Lead caregivers; and, 3) Provide a caring and compassionate presence. The results highlight the importance of various healthcare professionals’ roles in preparing family caregivers for a death. In doing so, both the dying and their caregivers may have a better end-of-life experience with improved bereavement outcomes. **Abstract:** <http://bit.ly/2JiywDg>

N.B. Selected articles on palliative and EoL care for people living with dementia noted in 21 October 2019 issue of Media Watch (#636, p.12).

Grief, bereavement, and coping with loss

PDQ SUPPORTIVE & PALLIATIVE CARE EDITORIAL BOARD | Online – 15 November 2019 – This PDQ cancer information summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about how individuals cope with grief, bereavement, and mourning. It is intended as a resource to inform and assist clinicians who care for cancer patients. It does not provide formal guidelines or recommendations for making healthcare decisions. This summary is reviewed regularly and updated as necessary by the PDQ Supportive & Palliative Care Editorial Board, which is editorially independent of the National Cancer Institute (NCI). The summary reflects an independent review of the literature and does not represent a policy statement of NCI or the National Institutes of Health. This summary first defines the constructs of grief, mourning, and bereavement. It then distinguishes the grief reactions of anticipatory grief, prolonged complicated grief, normal or common grief, models of normal grief, and complicated or prolonged grief. Psychosocial and pharmacologic treatments are explained. The important developmental issues of children and grief are presented, and a section on cross-cultural responses to grief and mourning concludes the summary. The information combines theoretical and empirical reviews of the general literature on grief, bereavement, and mourning and is not specific to loss via cancer. Unless otherwise stated, evidence and practice issues as they relate to adults are discussed. The evidence and application to practice related to children may differ significantly from information related to adults. When specific information about the care of children is available,

it is summarized under its own heading. **Full text (via Pub-Med):** <http://bit.ly/342tUJW>



Journal contents page: <http://bit.ly/2ToM4zl>

N.B. Selected articles on Elisabeth Kübler-Ross’ “five stages” model noted in 5 August 2019 issue of Media Watch (#625, pp.14-15).

Publishing Matters

‘**Journals in the field of death studies and bereavement. Where does *Bereavement Care* fit in?**’ (p.17) in *Bereavement Care*.

Intensity of care for cancer patients treated mainly at home during the month before their death: An observational study

LA PRESSE MÉDICALE | Online – 13 November 2019 – In France, home management during the last month of life is uncommon and even when it occurs, in one out of two cases patients pass away in a hospital setting. This study is an interrogation on medical choices, given the wish of many of the French to die at home and placing their choices in an international perspective. Among the 25,463 cancer patients who died in 2015, 54% of them died at home. They were slightly older (75 vs. 73 years) than those who died in hospital, had less frequently received hospital palliative care during the year preceding their deaths and had less often used medical transport to an emergency department, to hospital-based or community-based chemotherapy, to a general practitioner or to a community-based nursing service. However, when they consulted a general practitioner or a nurse during their last month of life, visits were more frequent. **Abstract:** <http://bit.ly/35iGbdv>

N.B. French language article.

Holding secrets while living with life-threatening illness: Normalizing patients' decisions to reveal or conceal

QUALITY HEALTH RESEARCH | Online – 19 November 2019 – Communicating openly and directly about illness comes easily for some patients, whereas for others fear of disclosure keeps them silent. In this article, the authors discuss findings about the role of keeping secrets regarding health and illness. These findings were part of a larger project on how people with life-threatening illnesses re-story their lives. Findings include case exemplars which suggest keeping secrets is a social practice that acts along continuums of connecting – isolating, protecting, harming, empowering, imprisoning. Keeping secrets about illness is a normative practice that is negotiated with each encounter. Findings call healthcare providers to rethink the role of secrets for patients by considering patient privilege, a person's right to take the lead in revealing or concealing their health and illness experience. **Abstract:** <http://bit.ly/2D9OSe4>

Conscience, tolerance, and pluralism in healthcare

THEORETICAL MEDICINE & BIOETHICS | Online – 19 November 2019 – Increasingly, physicians are being asked to provide technical services that many (in some cases, most) believe are morally wrong or inconsistent with their beliefs about the meaning and purposes of medicine. This controversy has sparked persistent debate over whether practitioners should be permitted to decline participation in a variety of legal practices, most notably physician-assisted suicide and abortion. These debates have become heavily politicized, and some of the key words and phrases are being used without a clear understanding of their meaning. In this essay, the author endeavors, firstly, to clarify the meaning of some of these terms: conscience, conscientious action, professional judgment, conscientious objection, conscience clauses, civil disobedience, and tolerance. He argues that use of the term conscientious objection to describe these refusals by healthcare professionals is mistaken and confusing. Secondly, relying on a proper understanding of the moral and technical character of medical judgment, the optimal deference that the state and markets ought to have toward professions, and general principles of Lockean tolerance for a diversity of practices and persons in a flourishing, pluralistic, democratic society, The author offers a defense of tolerance with respect to the deeply held convictions of physicians and other healthcare professionals who hold minority views on contested but legal medical practices. **Abstract (w. list of references):** <http://bit.ly/2D2Ukzj>



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.19.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL OF CLINICAL NURSING* | Online – 19 November 2019 – “**It is still intense and not unambiguous.**”: **A grounded theory study of nurses’ experiences in the euthanasia care process 15 years after legalisation [in Belgium].**’ Caring for a patient requesting euthanasia continues to be an intense experience characterized by ambivalence. The nature of euthanasia itself contributes to the intensity of this care process. The nurses [participating in this study] described euthanasia as something unnatural and planned that generated many questions and doubts. Nevertheless, most interviewees stated that they were able to contribute to a dignified end of life and make a difference, giving them a profound feeling of professional fulfilment. However, when nurses were not able to contribute to good euthanasia care, they struggled with strong negative feelings and frustrations. Although the results suggest some subtle shifts in nurses’ experiences over time, they do not indicate perceptions of euthanasia as a normal practice by the nurses involved. **Abstract:** <http://bit.ly/32ZeYLa>
- *NURSING INQUIRY* | Online – 22 November 2019 – ‘**Palliative sedation and medical assistance in dying: Distinctly different or simply semantics?**’ Both medical assistance in dying (MAiD) and palliative sedation (PS) in Canada are legitimate, legal options to alleviate suffering at the end of life (EoL). However, while some scholars and clinicians highlight the differences between these treatment options for unbearable suffering or intractable pain, others focus on the similarities. Notwithstanding the dissent that surrounds the perceived similarities and differences between PS and MAiD, there seems to be unanimity regarding the need to ensure access to comprehensive palliative care for all Canadians with adequate efforts to alleviate physical, psychosocial, and/or existential suffering being undertaken prior to considering either PS or MAiD... Greater understanding of both options and current debates is required to ensure patients, families, and clinicians have informed conversations. EoL decision-making warrants deep consideration and intentional planning by healthcare providers and the public alike so that the experience of death and dying may be as good as possible for all involved. **Full text:** <http://bit.ly/37wmReA>
N.B. Additional articles on PS noted in 11 November 2019 issue of Media Watch (#639, p.10).
- *PSYCHOLOGICAL INJURY & LAW* | Online – 15 November 2019 – ‘**Determination of competency for high-gravity life-death decision-making.**’ Just as the number of developed countries now legally permitting physician-assisted suicide (PAS) continues to grow, so too does the number of legal terms and definitions of medical assistance in dying (MAiD) and associated decisional capacity standards, illustrating the diversity of opinions on this topic. Of particular concern is the lack of a standard framework for clinical assessment of an individual’s competence to make this life and death high-gravity decision. This article provides context by reviewing background literature, current terminology, definitions, and evaluation models, as well as legislation regarding competence determination for choosing PAS and MAiD in general. A review of relevant current research is presented, with suggestions for future research and practice advances to fill the gap of much needed elucidation of this intensely debated topic. **Abstract (w. list of references):** <http://bit.ly/2CUnsJ3>

[Publishing Matters](#)

Journals in the field of death studies and bereavement. Where does *Bereavement Care* fit in?

BEREAVEMENT CARE, 2019;38(2-3):76-82. As this issue celebrates 60 years since the founding of Cruse, it is timely to review *Bereavement Care*, an important element in the development of the organisation, in the context of other journals with similar aims. The background to the publication of *Bereavement Care* is presented together with journals that contain a similar subject coverage. The way the journals are organised is briefly explored as well as some of their most cited and the most-read papers. Commentary on the latest issue of these journals is provided along with reflection on other sources of bereavement literature. Some suggestions for future topics are also included. **Abstract:** <http://bit.ly/2Xu5Htx>

N.B. Journal contents page: <http://bit.ly/2rXrJUJ>

Thompson Rivers University violated professor's academic freedom with suspension, Canadian Association of University Teachers report says

THE GLOBE & MAIL (Toronto, Canada) | Online – 19 November 2019 – Thompson Rivers University violated the academic freedom of a professor who criticized his colleagues for publishing in low-quality journals, an investigation by the Canadian Association of University Teachers (CAUT) has found. Derek Pyne, an associate professor of economics at the Kamloops [British Columbia] university, was suspended by the university and banned from campus in 2018, actions that he believed stemmed from his criticism of his colleagues. Prof. Pyne published a scholarly article in 2017 about the rewards of publishing in what are known as predatory journals,¹ which he defined as “journals that claim to be refereed but in reality publish articles in exchange for the payment of fees by authors.” The article studied a “small business school,” which he didn't name but was his own university's school of business and economics, the CAUT report states. The research got a lot of attention, including in international publications such as *The Economist* and *The New York Times*. Prof. Pyne believed the university's embarrassment lay at the root of a series of complaints about his behaviour that led to his suspension. The CAUT report found that Thompson Rivers has a weak institutional understanding of academic freedom, and that there were significant breaches of Prof. Pyne's academic freedom. <https://tgam.ca/346AcrM>

1. 'The rewards of predatory publications at a small business school,' *Journal of Scholarly Publishing*, 2017;48(3):137-160. [Noted in 15 May 2017 issue (#512, p.9)] **Abstract:** <http://bit.ly/2KB12Av>

[Media Watch: Editorial Practice](#)

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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](http://bit.ly/2ThijkC)

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/2NgALqN>

[Scroll down to 'Media Watch: GPs & Quality of Care']

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>]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2G2jqko>

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

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>

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