

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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Nearly one-third of children's hospitals [in the U.S.] do not have formalized palliative care service and advance care discussions tend to occur during relapses and treatment failures rather than at initial diagnosis.

'Lack of equality in end-of-life care for children' (p.11), *Pediatric Critical Care Medicine*, 2019;20(9):897-898.

Canada

Cancer overtakes heart disease as biggest killer in wealthy countries

CBC NEWS | Online – 3 September 2019 – Cancer has overtaken heart disease as the leading cause of death in wealthy countries and could become the world's biggest killer within just a few decades if current trends persist... Publishing the findings of two large studies ... scientists said they showed evidence of a new global "epidemiologic transition" between different types of chronic disease.¹ While cardiovascular disease remains, for now, the leading cause of mortality worldwide among middle-aged adults – accounting for 40% of all deaths – that is no longer the case in high-income countries, where cancer now kills twice as many people as heart disease... "Our report found cancer to be the second most common cause of death globally in 2017, accounting for 26% of all deaths. But as [heart disease] rates continue to fall, cancer could likely become the leading cause of death worldwide, within just a few decades," said Gilles Dagenais, a professor at Quebec's Laval University in Canada who co-led the work. Of an estimated 55 million deaths in the world in 2017, the researchers said, around 17.7

million were due to cardiovascular disease – a group of conditions that includes heart failure, angina, heart attack and stroke. Countries analyzed included Argentina, Bangladesh, Brazil, Canada, Chile, China, Colombia, India, Iran, Malaysia, Pakistan, Palestine, Philippines, Poland, Saudi Arabia, South Africa, Sweden, Tanzania, Turkey, United Arab Emirates and Zimbabwe. <http://bit.ly/2jT1ccq>

Specialist Publications

'The development and validation of updated palliative and end-of-life care competencies for medical undergraduates in Canada' (p.8), in *Journal of Palliative Medicine*.

'Medical assistance in dying: A political issue for nurses and nursing in Canada' (p.14), in *Nursing Philosophy*.

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1. 'Variations in common diseases, hospital admissions, and deaths in middle-aged adults in 21 countries from five continents (PURE): A prospective cohort,' *The Lancet*, 3 September 2019. **Full text:** <http://bit.ly/2IsDNz3>

Noted in Media Watch 2 September 2019 (#629, p.7):

- *PROGRESS IN PALLIATIVE CARE* | Online – 29 August 2019 – '**Integration of early supportive and palliative care in a patient's journey with cancer.**' Specialist palliative care (SPC) aims to effectively support the quality of life (QoL) of patients and those close to them through progressive, life-limiting disease. QoL requires a personalized approach to support and maintain it. Primarily achieved through the management of symptoms, both physical and psychological, alongside social and spiritual support, this approach is of the utmost importance to patients with advanced malignancy. Several randomized, controlled trials suggest earlier provision of SPC may increase QoL... **Abstract:** <http://bit.ly/2zxn15F>

Noted in Media Watch 27 May 2019 (#615, p.13):

- *JOURNAL OF SURGICAL ONCOLOGY* | Online – 18 May 2019 – '**Timing of palliative care: When to call for a palliative care consult.**' Palliative care (PC), unlike hospice, can be utilized concurrently with disease-modifying or curative therapies. Some of the benefits of PC include improved quality of life, less end-of-life treatment, and decreased medical costs. Furthermore, PC can help guide treatment decisions to be in line with patients' physical, psychological, and spiritual needs. On the basis of these benefits, the authors advocate for PC involvement early in the course of advanced malignancy and other terminal diagnoses. **Abstract:** <http://bit.ly/2VyVmtF>

U.S.A.

Is dying at home overrated?

THE NEW YORK TIMES | Online – 3 September 2019 – It is emotionally and intellectually compelling that patients should die in their own homes, surrounded by loved ones in a comfortable, familiar environment. For patients dying of end-stage disease, be it cancer, heart disease or something else, even the best hospitals are unlikely to be able to "fix" the underlying problem. We worry that people will go through expensive and potentially painful tests and interventions that have little chance of changing the ultimate outcome. And the opportunity costs are high; time waiting for a scan or procedure could be spent getting financial affairs in order or saying goodbye. While there are still those who subscribe to the idea that excellent healthcare demands doing everything possible to prolong a life, many doctors and patients now prefer a less intensive approach when time is short. Rates of hospice enrollment have increased and the home has re-emerged as a place to die, not only preferred by patients and families but also heavi-

ly recommended by clinicians... The system is imperfect, though. Unless a family has the significant resources necessary to hire aides or nurses, informal caregivers become responsible for nearly everything... These tasks often get harder as the dying person weakens. Most family members want to care for their loved ones at home, but many are unaware of caregiving's physical and emotional toll. And the length of time a patient spends in hospice care is difficult to predict, sometimes requiring caregivers to take significant time away from work or other family members. <https://nyti.ms/2krrXVB>

Specialist Publications

'Characterizing the financial value of in-home palliative care for patients, payers, and hospitals' (p.5), in *American Journal of Hospice & Palliative Medicine*.

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Noted in Media Watch 15 July 2019 (#622, p.10):

- *JOURNAL OF PSYCHOSOCIAL ONCOLOGY RESEARCH & PRACTICE*, 2019;1(1):e3. **‘Navigating the path to care and death at home – it is not always smooth: A qualitative examination of the experiences of bereaved family caregivers in palliative care.’** Understanding the complexities of end-of-life care and the support needs of family caregivers in the home setting could improve services. Relationships where families and patients are partnered with, mentored, empowered, and feel comfortable with clinicians and volunteer caregivers are valued. Flexible practical assistance is valued highly and care arrangements that are not flexible may be more harmful than helpful for some families. Models of care that are based on the assumption that home death is straightforwardly beneficial may cause unintended consequences. **Full text:** <http://bit.ly/2xJ6YRq>

Noted in Media Watch 6 May 2019 (#613, p.12):

- *PALLIATIVE MEDICINE* | Online – 3 May 2019 – **“‘It all depends!’: A qualitative study of preferences for place of care and place of death in terminally ill patients and their family caregivers.’** It is often suggested terminally ill patients favour end-of-life care at home. Yet, it is unclear how these preferences are formed, if the process is similar for patients and family caregivers, and if there are discrepancies between preferences for place of care and place of death. The process of forming location preferences by the participants in this study was shaped by uncertainty relating to the illness, the caregiver and the services. Patients and caregivers dealt with this uncertainty on a level of thoughts, emotions, and actions. At the end of this process, patients and caregivers expressed their choices as contextual, personal, relational, conditional and flexible preferences. **Abstract:** <http://bit.ly/2IWKALQ>

Beaufort study helps doctors approach patients with cultural understanding at end of life

ALABAMA | *The Post & Courier* (Charleston, South Carolina) – 1 September 2019 – Four physicians and several Beaufort residents all gathered at the historic Penn Center on a recent Friday morning. One group was there to teach, the other to learn. “I just want them to understand culture,” said Dr. Ronit Elk, a professor from the University of Alabama at Birmingham who is leading the research project. “Physicians aren’t trained in many cultures.” For the last six years, Elk and her colleagues have worked with Beaufort residents on a study that they hope improves palliative care (PC) for people with a serious illness. One of the goals is to come up with a proven list of guidelines for PC physicians to help them work better with patients from differing cultures. The original study, which took five years, involved Beaufort residents, a singular physician from Chicago, and Beaufort Memorial Hospital.¹ The groups met once a month for two and a half years and came up with separate guidelines for each demographic. The Chi-

cago physician, Dr. Josh Hauser, then teleconferenced with PC patients at Beaufort Memorial to provide culturally based PC based on those guidelines. The program was well received, so they decided to expand it. Now, they have funding from the National Institutes of Health for five more years. They also have more physicians and hospitals in Alabama and Mississippi who are taking part. <http://bit.ly/2jXYqCO>

[Specialist Publications](#)

‘Another example of race disparities in the U.S. healthcare system’ (p.7), in *Clinical Journal of American Society of Nephrology*.

‘U.S. hospice structure and its implications for the “right to die” debate’ (p.13), in *Journal of Bioethical Inquiry*.

1. ‘A community-developed, culturally-based palliative care program for African American and white rural elders with a life-limiting illness: A program by the community for the community,’ *Narrative Inquiry in Bioethics*, 2017;7(1):36-40. [Noted in 24 July 2017 issue of Media Watch (#522, p.13)] **Full text:** <http://bit.ly/2ksej17>



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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **THE NEW YORK TIMES** | Online – 6 September 2019 – ‘**The role of nurses when patients decide to end their lives.**’ As access to aid in dying (AiD) expands this fall, one in five Americans will live in a state that permits legal AiD. Some hospitals and hospices see medical AiD as conflicting with their traditional mission of protecting life and avoiding harm to patients. Those that are faith-based typically follow church policy against AiD. Some have policies that forbid nurses even to discuss end of life options. Others hold a “neutral” stance on AiD, but bar doctors or nurses from being in the room while a patient self-ingests the medication and begins the dying process. In June, the American Nurses Association passed a position statement providing guidance on the nurse’s role in medical AiD...¹ A 2014 study ... analyzed 30 policies from members of the hospice and palliative care organization in Washington, where AiD has been available since 2009.² Of the policies analyzed, 78% prevented nurses or other staff members from being present during or after the prescription was taken. The authors described the policies as “relatively silent” about the rationale for their decisions, but some referred to medical AiD as being “outside the scope of hospice practice.” Others did not want to be seen as “taking sides.” The hospices that allowed staff members to be present made note of the core hospice value of not abandoning patients. <https://nyti.ms/2kvb6kV>
 1. The nurses role when a patient requests medical aid in dying,’ American Nurses Association, June 2019. **Download/view at:** <http://bit.ly/2k0SQQ4>
 2. ‘Dignity, death, and dilemmas: A study of Washington hospices and physician-assisted death.,’ *Journal of Pain & Symptom Management*, published online 8 July 2013. [Noted in 15 July 2013 issue of Media Watch (#314, p.16)] **Full text:** <http://bit.ly/2IHqASU>
- **KAISER HEALTH NEWS** | Online – 30 August 2019 – ‘**Firing doctor, Christian hospital sets off national challenge to aid-in-dying laws.**’ A Christian-run health system in Colorado has fired a veteran doctor who went to court to fight for the right of her patient to use the state’s medical aid-in-dying law, citing religious doctrine that describes “assisted suicide” as “inherently evil.” Centura Health Corporation this week abruptly terminated Dr. Barbara Morris, 65, a geriatrician with 40 years of experience, who had planned to help her patient, Cornelius Mahoney, 64, end his life at his home. Mahoney, who has terminal cancer, is eligible to use the state’s law, overwhelmingly approved by Colorado voters in 2016. The growing number of state aid-in-dying provisions are increasingly coming into conflict with the precepts of faith-based hospitals, which oppose the practice on religious grounds. <http://bit.ly/2IzNhbF>

International

Insight into palliative care

IRELAND | *View* – 2 September 2019 – The All Ireland Institute of Hospice & Palliative Care, as part of Ireland’s national palliative care (PC) week (8-14 September 2019), is the sponsor of the latest edition of the online magazine *View*, which focuses on the end-of-life care and some of the misconceptions about about hospice and PC. The theme of the PC week is “surrounding you with support.” **Download/view the complete issue online at:** <http://bit.ly/2IUmqYI>

Specialist Publications

‘**Dying in long-term care facilities in Europe: The PACE epidemiological study of deceased residents in six countries**’ (p.5), in *BMC Public Health*.

‘**Barriers to palliative care in pediatric oncology in Switzerland: A focus group study**’ (p.11), in *Journal of Pediatric Oncology Nursing*.

‘**Integrating palliative care and symptom relief into responses to humanitarian crises**’ (p.9), in *Medical Journal of Australia*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Western Australia) | WA Today (Perth) – 3 September – ‘**Polling reveals country voters want palliative care fixed before euthanasia legalised.**’ Regional Western Australians want palliative care (PC) fixed before the introduction of euthanasia, a poll of almost 2,000 voters ... has revealed. The research, which was commissioned by a group of doctors, lawyers and health professionals called the End-of-Life Choices Working Group, has found only one person out of every four believe euthanasia should be legalised before PC is improved across the state. Out of all pro-euthanasia voters, 73% believe PC ought to be improved before euthanasia becomes legal. The polling also revealed 64% of people did not support allowing euthanasia if a person’s loved ones had not been notified, a safeguard the Western Australia Palliative Medicine Specialists Group said was missing in the legislation before State’s Parliament. The state government will spend \$206 million over the next four years on PC, including \$12 million in total for regional PC services. <http://bit.ly/2lwtWZO>

N.B. Palliative Care Australia has updated its position statement on voluntary assisted dying and palliative care. **Download/view at:** <http://bit.ly/2HW3b9a>

Specialist Publications

Characterizing the financial value of in-home palliative care for patients, payers, and hospitals

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 2 September 2019 – The holistic and multidisciplinary approach of in-home palliative care (IHPC) is known to offer high-quality and cost-effective care for patients at the end of life. However, the financial benefits of upstream IHPC programs to hospitals, patients, and payers have not been fully characterized for patients with comorbid chronic conditions. A structured retrospective patient record review was conducted on the number of emergency department (ED) visits, number of inpatient hospitalizations, hospital length of stay (LOS), and payments made to the hospital for all patients enrolled in an IHPC program between 1 January 2016 and 30 June 2016. After patients enrolled in IHPC, average ED and inpatient utilization declined significantly by 41% and 71%, respectively. The payers for

healthcare services realized a significant decline of US\$2,201 in hospital payments per patient per month. Inpatient LOS was also significantly lower than expected once patients enrolled in the program. As the need for chronic disease management continues to grow, managers of health systems, managed care organizations, and home health agencies should be cognizant of the financial value that IHPC has to offer. **Abstract:** <http://bit.ly/2krslU5>

Publishing Matters

‘**Perspectives from authors and editors in the biomedical disciplines on predatory journals: Survey study**’ (p.14), in *Journal of Medical Internet Research*.

Dying in long-term care facilities in Europe: The PACE epidemiological study of deceased residents in six countries

BMC PUBLIC HEALTH | Online – 30 August 2019 – Although there are important country differences, the population currently living and dying in long-term care (LTC) facilities is very complex, displaying multiple diseases with considerable cognitive and functional impairment and high levels of dementia. Given the complex care needs of LTC facility residents, palliative care (PC) is the most appropriate care approach for this population and education of nursing staff should include learning skills to meet these needs. Since many residents also suffer from advanced dementia at the time of death, the authors recommend that policies addressing this sector highlight the need for the integration of high-quality PC together with high-quality dementia care. This study [of 322 LTC in Belgium, Finland, Italy, The Netherlands, Poland and England] is an excellent starting point for monitoring populations of people who die in LTC facilities. **Full text:** <http://bit.ly/2UULmow>

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Noted in Media Watch 8 July 2019 (#621, p.11):

- *PALLIATIVE MEDICINE* | Online – 1 July 2019 – ‘**Palliative care provision in long-term care facilities differs across Europe: Results of a cross-sectional study in six European countries.**’ The authors included 1,298 residents in 300 facilities, of whom a majority received palliative care (PC) in most countries (England: 72.6%; Belgium: 77.9%), except in Poland (14.0%) and Italy (32.1%). PC typically started within 2 weeks before death and was often provided by the treating physician (England: 75%; the Netherlands: 98.8%). A PC specialist was frequently involved in Belgium and Poland (57.1% and 86.7%). The late initiation of PC (especially when advance care planning is lacking) and PC for residents without cancer, dementia or closely involved relatives deserve attention in all countries. **Abstract:** <http://bit.ly/2J1oeYg>

N.B. Additional articles on PC in LTC facilities noted in this issue of Media Watch.

Physicians’ perceptions of palliative sedation for existential suffering: A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 3 September 2019 – Palliative sedation for existential suffering (PS-ES) is a controversial clinical intervention. Empirical studies about physicians’ perceptions do not converge in a clear position and current clinical practice guidelines do not agree either regarding this kind of intervention. The authors’ literature search yielded 17 publications published between 2002 and 2017. Physicians do not hold clear views or agree if and when PS-ES is appropriate. Case-related and individual-related factors that influenced physicians’ perceptions were identified. There is still no consensus regarding criteria to distinguish between necessary and sufficient conditions for invoking PS-ES. Some alternatives to PS-ES were identified. Further research is necessary to understand factors that influence physicians’ perceptions and philosophical-ethical presuppositions underlying this perceptions. **Abstract:** <http://bit.ly/2lwZRsm>

Noted in Media Watch 18 February 2019 (#602, p.14):

- *JOURNAL OF PALLIATIVE CARE* | Online – 13 February 2019 – ‘**The use of palliative sedation to treat existential suffering: A scoping review on practices, ethical considerations, and guidelines.**’ Four themes were identified as key findings: 1) Ethical considerations; 2) The role of the health-care provider; 3) The need for multidisciplinary care teams; and, 4) Existential suffering’s connection to religiosity and spirituality. Palliative sedation to treat existential refractory symptoms was labelled a controversial practice. A shortage of evidence-based resources limits the current literature’s ability to inform policy and clinical practice. **Abstract:** <http://bit.ly/2UUHZ7d>

General practitioners’ engagement in end-of-life care: A semi-structured interview study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 3 September 2019 – Early identification of approaching end-of-life (EoL) and care planning improve outcomes at the EoL. Nevertheless, the majority of people who die are not identified in time to enable appropriate care planning. The authors describe the challenges general practitioners (GPs) found in providing EoL care; what prompted GPs to identify and discuss approaching EoL with their patient and how their practice changed. When a life-limiting prognosis was articulated, GPs integrated EoL care into their clinical care directly. Care often included a care plan developed in consultation with the patient. Even when death was not articulated, GPs were aware of approaching EoL and changed their focus to comfort of the patient. GPs generally had an informal care plan in mind, but this developed gradually and without discussing these plans with the patient. How GPs provided EoL care depended primarily on patient traits (e.g., willingness to discuss physical decline) and the GP’s characteristics (e.g., experience, training and consulting style). GPs were aware of their patients’ approaching EoL and care was adjusted accordingly. However, under certain circumstances this was not explicitly articulated and discussed. It is not clear if implicit but unarticulated EoL care is sufficient to meet patients’ needs. Future studies should investigate this. **Abstract:** <http://bit.ly/2kfpeyJ>

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Noted in Media Watch 2 September 2019 (#629, p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 29 August 2019 – ‘**General practice physicians’ and nurses’ self-reported multidisciplinary end-of-life care: A systematic review.**’ General practitioners (GPs) report a central role in symptom management, treatment withdrawal, non-malignant disease management and terminal sedation. Information provision included breaking bad news, prognosis and place of death. Psychosocial concerns were often addressed. Quality of communication depended on GP-patient relationships and GP skills. Challenges were unrealistic patient and family expectations, family conflict and lack of advance care planning. **Abstract:** <http://bit.ly/2UfS6o0>

Noted in Media Watch 20 May 2019 (#614, p.10):

- *GP* | Online – 16 May 2019 – ‘**Most general practitioners have too little time to discuss end-of-life care.**’ Amid rising pressure on general practice, 72% of the 370 GPs who responded to a survey by the medico-legal organisation Medical Protection said they did not have enough time to discuss end-of-life care (EoLC). The findings come after the Royal College of General Practitioners published quality improvement standards for EoLC in general practice, alongside research showing that four in five GPs felt that heavy workload left them unable to dedicate as much time as they would like to EoLC.¹ The poll found 55% of GPs felt comfortable talking to patients about dying. <http://bit.ly/2HnyNms>

1. ‘Palliative and End-of-Life Care Toolkit,’ Royal College of General Practitioners, noted in 18 February 2019 issue of Media Watch, #602, p.11. **Download/view at:** <http://bit.ly/2G12LTJ>

Another example of race disparities in the U.S. healthcare system

CLINICAL JOURNAL OF AMERICAN SOCIETY OF NEPHROLOGY, 2019;30(9):1553-1554. The medical literature is rife with studies showing how minority groups fare worse than their white counterparts in arguably every outcome and from cradle to grave. Black babies are twice as likely to die as white babies. Black people choose hospice a third less often than white people and disenroll at higher rates. Further, many a researcher has built an academic career pointing out these disparities, without ever suggesting real ways to overcome them. Wen *et al* provide us with yet another example.¹ When they examined trends of palliative care (PC) utilization among patients on dialysis who were hospitalized between 2006 and 2014, they found PC utilization was several-folds lower than for other serious illnesses, that utilization increased over time, and that Blacks and Hispanic patients were 28% to 54% less likely to use PC services, respectively, than white patients. These disparities persisted among all hospital and patient-level characteristics, except possibly for age which was not shown. Given that those who did not receive PC were younger and that Black and Hispanic people tend to progress to end stage kidney disease on dialysis faster and at younger ages than their white counterparts (another disparity!), this may explain some of the disparity. **Full text:** <http://bit.ly/2HCG2b7>

1. ‘Trends and racial disparities of palliative care use among hospitalized patients with end stage kidney disease on dialysis,’ *Clinical Journal of American Society of Nephrology*, 2019;30(9):1687-1696. [Noted in 12 August 2019 issue of Media Watch (#626, p.8)] **Full text:** <http://bit.ly/2UI9lnQ>

N.B. Additional articles on ethnic and racial disparities in the provision and delivery of PC in the U.S. noted in 8 July 2019 issue of Media Watch (#621, p.7).

Addressing the burden of illness in adults with cystic fibrosis with screening and triage: An early intervention model of palliative care

JOURNAL OF CYSTIC FIBROSIS | Online – 27 August 2019 – Novel models that improve generalist-level palliative care for cystic fibrosis (CF) are needed to address the burden of this illness. A screening-and-triage model has the potential to identify clinical problems requiring immediate follow-up by CF professionals. This study describes such a model and its immediate impact on care delivery for CF patients during a two-year period. A total of 1,015 monthly surveys were completed by 74 patients; 634 had indicators of concern; and, 164 surveys had indicators for two consecutive surveys (e.g., global distress,

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pain, dyspnea, and psychological symptoms). The 164 attempted triages yielded 84 completed triages (51.2%), of which 39 (46.4%) required prompt follow-up. In multivariable analyses, older patients and those with higher symptom distress at baseline were more likely to require prompt follow-up. Web-based screening that assesses varied domains of distress or burden can identify a subset of CF patients whose clinical problems may benefit from immediate medical or psychological attention. Additional investigations should improve screening efficiency. **(Abstract w. link to references):** <http://bit.ly/2UjSt0T>

Noted in Media Watch 26 August 2019 (#628, p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 19 August 2019 – ‘**Opportunities to improve utilization of palliative care among adults with cystic fibrosis: A systematic review.** While 43% to 65% of adults with cystic fibrosis had contemplated completing advance care planning (ACP), the majority only completed ACP during their terminal hospital admission. Patients reported high prevalence of untreated symptoms, with adequate symptom control reported in 45% among those with dyspnea, 22% among those with pain, and 51% among those with anxiety and/or depression. Prevalence of in-hospital death ranged from 62% to 100%, with a third dying in the intensive care unit (ICU). Treatment from a palliative care specialist was associated with a higher prevalence of patient completion of advanced directives, decreased likelihood of in-ICU death and decreased use of mechanical ventilation at end-of-life. **Abstract (w. link to references):** <http://bit.ly/2Hu7ecn>

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

The development and validation of updated palliative and end-of-life care competencies for medical undergraduates in Canada

JOURNAL OF PALLIATIVE MEDICINE | Online – 6 September 2019 – In 2008, a Canadian strategy, ‘Educating Future Physicians in Palliative & End-of-Life Care’ (EFPPEC) project published national medical undergraduate competencies for palliative and end-of-life care. Since that time, there have been several changes in the practice environment. To formally incorporate these changes and also update the competencies for EFPPEC, an EFPPEC update project team was established in 2017. The EFPPEC update document in English was finalized in June 2018, and subsequent minor amendments to the French version were completed in January 2019. This report describes the process and also shares the new updated EFPPEC competencies with the wider palliative care community. **Abstract:** <http://bit.ly/2kyGsqT>

Spiritual dimension at the end of life: A phenomenological study from the caregiver’s perspective

JOURNAL OF RELIGION & HEALTH | Online – 29 August 2019 – The lives of healthy and sick people are structured according to a variety of conceptual matrices. One of these matrixes consists of philosophical, spiritual, and religious convictions, this being especially relevant in the process of the end of life (EoL). The objective of the study was to understand the meaning that individuals at the EoL and the relatives of such individuals award spiritual and/or religious beliefs through an examination of caregiver narratives. A change of paradigms is necessary in which, among other elements, the focus of palliative care is centered on the ability to address these spiritual needs, and healthcare professionals are trained to assist in the provision of such care. Another important consideration is the inequality of spiritual support provided by clergy from various religions. At least in the cultural context of the research, Catholic chaplains were the only institutional figures whose presence was assumed necessary by health organizations. However, the cultural and/or religious diversity in the autonomous community in which the study was conducted is increasingly broad and complex. It appears necessary to incorporate a variety of clergies in health units so that all patients may find support, whether in terms of companionship or celebration. **Abstract (inc. list of references):** <http://bit.ly/2LcXAwS>

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Would this article be of interest to a colleague?

Noted in Media Watch 19 August 2019 (#627, p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 13 August 2019 – ‘**Spiritual distress in family members of critically ill patients: Perceptions and experiences.**’ Spiritual distress among family members of patients in the intensive care unit (ICU) has not been well characterized. This limits clinicians’ understanding of how to best offer support. The experience of spiritual distress was variably described in this study by all three groups interviewed through concepts, modulators, expressions and manifestations, and ways in which spiritual distress was addressed. This study provides a rich description of how spiritual distress is experienced by family members of ICU patients, and how spiritual health practitioners and clinicians recognize spiritual distress and offer support. These findings will help inform clinician education and initiatives to better support families of critically ill patients. **Abstract:** <http://bit.ly/2YOBjxX>

N.B. Selected articles on spiritual care in palliative and end-of-life care noted in 12 August 2019 issue of Media Watch (#626, p.9). Additional articles on the role of chaplains in palliative care noted in 6 May 2019 issue of Media Watch (#613, p.8).

Integrating palliative care and symptom relief into responses to humanitarian crises

MEDICAL JOURNAL OF AUSTRALIA, 2019; 211(5):201-203. The medical and moral imperative that palliative care (PC) be integrated into standard responses to humanitarian crises can be fulfilled by basic training and an essential set of medicines, equipment, social support and protocols. Humanitarian crises often cause both extensive loss of life and widespread suffering. Yet humanitarian crisis response virtually never fully integrates PC, the discipline devoted to preventing and relieving suffering. Recently, the World Health Organization (WHO) recognised the necessity of integrating PC and symptom relief into responses to humanitarian crises of all types and published a guide to this integration. In this article, the authors summarise the WHO recommendations, explain why inclusion of PC as an essential part of humanitarian response is medically and morally imperative, and describe how to ensure that PC is accessible for those affected by humanitarian crises. **Abstract:** <http://bit.ly/2ZGvFcJ>

N.B. Additional articles on integrating PC and symptom relief into responses to humanitarian emergencies and crises

Improving access to paediatric palliative care for vulnerable populations in southern countries

MÉDECINE PALLIATIVE | Online – 3 September 2019 – In a global context where inequality of access to health is current and where access to opiates and palliative care (PC) remains largely non-existent, health professionals are committed to improving access to paediatric PC. Solicited by partners and having strong expertise on the subject of paediatric PC through its collaborators, the non-governmental organization Médecins du monde-Suisse started at the end of 2014 a program to promote access in Kinshasa, Democratic Republic of Congo; Yaoundé, Cameroon; Lomé, Togo; and, Managua, Nicaragua. The aims of this project are to reinforce local initiatives in paediatric PC, help to perpetuate the offers of healthcare and promote exchanges within a network of professionals from both north and south while involving hospital and ministerial institutions. **Abstract:** <http://bit.ly/2kpcWDK>



Media Watch: On Humanitarian Crises

Palliative care is entering the “culture” of humanitarian organizations. Morbidity and mortality caused by non-communicable diseases are about to overtake infectious diseases in adults, and the epidemiology of diseases is shifting toward chronic conditions even in low-income countries where disasters and armed conflicts are common. <http://bit.ly/2G8FVUj>

N.B. Scroll down to ‘Media Watch: On Humanitarian Crises’

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N.B. French language article. Additional articles on PC: in the Democratic of Congo noted in 15 May 2017 issue of Media Watch (#512, pp.13-14); and, in Cameroon noted in 26 August 2019 issue of Media Watch (#628, p.12).

Noted in Media Watch 8 October 2019 (#584, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 1 October 2018 – ‘**Is palliative care cost-effective in low-income and middle-income countries? A mixed-methods systematic review.**’ Cost-effectiveness models are lacking in low-income and middle-income countries and with them, the impetus and funding to expand PC delivery. This review highlights the extraordinary need for robust cost-effectiveness analysis of PC in low-income and middle-income countries in order to develop health economic models for the delivery of PC, direct resource allocation and guide healthcare policy for PC delivery in low-income and middle-income countries. **Abstract:** <http://bit.ly/2jZqxBz>

Noted in Media Watch 20 February 2017 (#500, p.8):

- *BMJ GLOBAL HEALTH* | Online – 14 February 2017 – ‘**What is the value of palliative care provision in low-resource settings?**’ While proven to be “cost-effective” in high-income settings based on principles of cost avoidance, the costs of illness for incurable disease in low-resource settings is largely unknown. The critical absence of palliative care (PC) services in low-resource settings results in significant costs being absorbed by the individual, family and local community. In considering the direct, indirect and broader societal costs of incurable disease in low-resource countries, PC should be considered as a poverty-reduction strategy. **Full text:** <http://bit.ly/2kucPXz>

Moral ambiguity in media reports of dying alone

MORTALITY | Online – 3 September 2019 – More older people are living alone in the U.K., thereby increasing the prospect of dying alone at home. Lone deaths tend to be regarded as bad deaths, in that they contravene notions of accompaniment and open awareness espoused in U.K. end-of-life care policies. The authors describe a media analysis of dying alone conducted in two phases. First, they revisited a previous media analysis to examine whether news reporting of dying alone has changed. Second, they focussed on a single case study to explore how an account of a lone death unfolded during the days following its discovery. The authors found that dying alone remains a threat to individual and collective moral reputations. However, they also identified reports in which dying alone was presented as acceptable in some circumstances, and as congruent with aspects of a good death. The authors suggest that dying alone can be made good through media reporting, reflecting the individual choice and autonomy associated with a good death. There is potential for news media to revise cultural scripts of dying, largely based on the experiences of people dying under medical supervision. **Abstract:** <http://bit.ly/2ksqSNq>

Noted in Media Watch 18 December 2017 (#543, p.17):

- *MORTALITY* | Online – 13 December 2017 – “‘**I’ve no fear of dying alone**’”: **Exploring perspectives on living and dying alone.**’ People do often die alone, both in institutional and domestic settings. Participants in this study reacted in differing ways to threats to their independence, but all utilised a form of relational reflexivity when considering the effect their actions might have on others. The nurses would prefer no one to die alone, but believed they had seen patients managing their own dying so that they could be alone at the moment of death. The paper suggests that dying alone may be a problem for survivors, rather than for the person who is dying. **Abstract:** <http://bit.ly/2kuvZq7>

[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>



If cemeteries could talk: A discourse-analytical analysis of epitaphs

OMEGA – JOURNAL OF DEATH & DYING | Online – 5 September 2019 – Death discourse provides interesting material to determine how societies and cultures cope with death and the sorrow of losing a beloved one. Several aspects can be analyzed: content, language, design, and so on. This article describes a diachronic bottom-up analysis of the metaphorical language in 150 epitaphs from Belgian cemeteries. The analysis allows us to determine whether attitudes toward death and the taboo to talk directly about it have changed. Based on the existing frameworks, 13 recurring metaphors were identified and analyzed. Their occurrences are linked to the period in which they were written and the age and the gender of the deceased. Epitaphs are a stable genre on all levels of analysis. The results indicate that people are still reluctant to talk in a straightforward way about death as metaphors with positive connotations prevail.

Abstract: <http://bit.ly/2IAaD18>

Falling short: Lack of equality in end-of-life care for children

PEDIATRIC CRITICAL CARE MEDICINE, 2019;20(9):897-898. Unfortunately, many children die, even those when death is expected, without benefiting from palliative care (PC) services. Likewise, pediatricians frequently feel burdened with providing arduous, “unnecessary” treatment that adversely impacts the quality of life of critically or terminally ill children. This is due partly to persistent deficiencies in some of the identified facts that influence end-of-life care (EoLC): knowledge regarding and availability of PC services and hospice programs for children. The current American Academy of Pediatrics PC guideline recommends PC be available for all children with life-threatening or terminal conditions and offered at the time of diagnosis. Despite this, nearly one-third of children’s hospitals [in the U.S.] do not have formalized PC service and advance care discussions tend to occur during relapses and treatment failures rather than at initial diagnosis. Also, impeding pediatric EoLC are frequent stipulations of medical insurance plans that insurance benefits only cover hospice care when life expectancy is under six months. This poses major issues in childhood diseases, as survival is frequently difficult to predict. Failure to facilitate timely EoLC presents missed opportunities to holistically treat our patients. **First page view:** <http://bit.ly/2IF9Mfj>

Noted in Media Watch 10 September 2018 (#580, p.5):

- *CHILDREN* | Online – 31 August 2018 – ‘**Delivering pediatric palliative care: From denial, palliophobia, pallilalia to palliative.**’ In the U.S. alone, more than 42,000 children die every year, half of them infants younger than one year. Advanced interdisciplinary pediatric palliative care (PPC) for children with serious illnesses is now an expected standard of pediatric medicine. Unfortunately, in many institutions there remain significant barriers to achieving optimal care related to lack of formal education, reimbursement issues, the emotional impact of caring for a dying child, and most importantly, the lack of interdisciplinary PPC teams with sufficient staffing and funding. **Full text:** <https://goo.gl/rvFUJ8>

Related

- *JOURNAL OF PEDIATRIC ONCOLOGY NURSING* | Online – 3 September 2019 – ‘**Barriers to palliative care in pediatric oncology in Switzerland: A focus group study.**’ Analysis revealed eleven barriers: lack of financial resources, lack of pre-job education regarding pediatric palliative care, lack of awareness in politics and policy making, absence of a well-established nationwide bridging care system, insufficient psychosocial and professional supervision for staff, understaffing, inadequate infrastructure of hospitals, asymmetry of factual and emotional knowledge between parents and providers, cultural aspects, irrational parental hopes, and “the unspoken.” **Abstract:** <http://bit.ly/2IBdVBi>
- *MÉDECINE PALLIATIVE* | Online – 4 September 2019 – ‘**The messenger child: A transcultural approach to the end of life.**’ The author introduces the theoretical and technical foundations of the transcultural mediation approach as it is implemented with palliative care teams. Accompanying a family in this event is a challenge for all care teams and can be even more complex when caregivers and parents do not share the same cultural references. In situations of therapeutic impasse, taking into account the cultural fact ... can not only enrich the medical interpretation but also make possible a real encounter between the patient and his doctor. **Abstract:** <http://bit.ly/2k3KGXc>

N.B. French language article.

Cont.

- *NURSING CHILDREN & YOUNG PEOPLE* | Online – 4 September 2019 – ‘**Withdrawal of treatment from critically ill children: Legal and ethical issues.**’ The principle of best interests was central to three recent high-profile legal cases [in the U.K.] and raised questions about how this is demonstrated in healthcare for children whose treatment may be of no benefit to them. This article discusses the legal and ethical aspects of caring for such children. Nurses are important advocates and should balance their obligation to deliver holistic and family-centred care with that of keeping the child as the central focus, particularly with decision-making. **Abstract:** <http://bit.ly/2IWxOTj>
- *NURSING CHILDREN & YOUNG PEOPLE* | Online – 3 September 2019 – ‘**Approaches to community-based palliative care provision by children’s hospices in the U.K.**’ An internet-based questionnaire survey was sent to all children’s hospices in the U.K... Responses were received from 14 (26%) of the hospices. 1,618 children and their families were being cared for by these hospices, of whom 825 received care at home. Registered nurses constituted the greatest proportion of staff and were employed by all teams. Care provided at home was broadly split into two categories: planned short breaks and responsive palliative nursing. **Abstract:** <http://bit.ly/2ktQxoO>
- *PEDIATRICS* | Online – 4 September 2019 – ‘**Failure to provide adequate palliative care may be medical neglect.**’ Which treatments properly fall within the realm of shared decision-making in which parents can decide whether to accept doctors’ recommendations? Which treatments are so clearly in the child’s interest that it would be neglectful to refuse them? The authors present a case of an adolescent with chronic pain who is terminally ill. Her parents were not adherent to recommended analgesia regimens. Her palliative care team had to decide whether to report the case to [the U.S.] Child Protective Service. **Abstracts:** <http://bit.ly/2kiekbz>
- *TRANSLATIONAL SCIENCE OF RARE DISEASES* | Online – 24 August 2019 – ‘**How do I treat when there is no treatment?**’ Many children in hospice care have rare diseases. The authors discuss the importance of genetic counseling and describe the basic tenants of palliative care. By approaching this topic from a rare disease perspective, they discuss the unique features of improving quality of life for patients and families and the role of self-care in preventing care provider burnout of families and medical providers. The thoughtful approach to palliation in rare diseases is essential to optimize the experience for all participants in a patient’s shortened life. **Full text:** <http://bit.ly/2Uj10ks>

Medicinal cannabis and cannabis-based medication: An appeal to physicians, journalists, health insurances, and politicians for their responsible handling

DER SCHMERZ | Online – 2 September 2019 – Since the adoption of the law of March 2017, any German physician can prescribe medical cannabis flowers and cannabis-based magistral and finished medicinal products. No specific indications for prescriptions are provided in the law. The statutory health insurance companies bear the costs once an application for cost coverage has been approved by the Medical Service of the Health Funds. The German associations of psychiatry, neurology, palliative care, addictology, and pain medicine are watching these developments in the media, politics, and medical world with concern due to: the option to prescribe cannabis flowers despite the lack of sound evidence and against the recommendations of the German Medical Association; the lack of distinction between medical cannabis flowers and cannabis-based magistral and finished medical products; the indiscriminately positive reports on the efficacy of cannabis-based medicines for chronic pain and mental disorders; the attempts by the cannabis industry to influence physicians; the increase in potential indications by leaders of medical opinion paid by manufacturers of cannabis-based medicines. The medical associations make the following appeal to journalists: To report on the medical benefits and risks of cannabis-based medicines in a balanced manner. To physicians: to prescribe cannabis-based medicines with caution; to prefer magistral and finished medicinal products over cannabis flowers. To politicians: to consider data according to the standards of evidence-based medicine when making decisions and provide financial support for medical research into cannabis-based medicines. **Abstract (w. list of references):** <http://bit.ly/2krbSzn>

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Media Watch: Behind the Scenes
<http://bit.ly/2MwRRAU>

Related

- *PUBLIC POLICY & AGING REPORT*, 2019;29(3):95-100. **'The role of cannabis in improving pain and symptom management in end-of-life care.'** How can we improve pain management at the end of life? End-of-life care (EoLC) begins once patients have stopped treatment to cure or control their disease, and is inclusive of medical, emotional, social, and spiritual support for patients and their families. Individuals may be thinking about EoLC as their symptoms decline and they reconcile the reality that they are dying. EoLC is most concerned with minimizing pain and suffering through symptom management, and helping a person adjust to a new state of living... **Introduction:** <http://bit.ly/2ZtP1Xe>

N.B. Additional articles on cannabinoids and cannabis-based drugs in hospice and palliative medicine noted in 2 September 2019 issue of Media Watch (#629, pp.9-10).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMC MEDICAL ETHICS* | Online – 2 September 2019 – **'Ghent University Hospital's protocol regarding the procedure concerning euthanasia and psychological suffering.'** The protocol stipulates several due care criteria that go beyond the requirements of the Belgian Euthanasia Law. For instance, the legally required first and second consulted physicians should all be psychiatrists and be affiliated with a psychiatry department of a Flemish university hospital. Moreover, euthanasia for psychological suffering can only be performed if the advices of these consulted physicians are positive. Importantly, preliminary reflection by the multidisciplinary Hospital Ethics Committee was introduced to discuss every request for euthanasia for psychological suffering coming from outside the hospital. In this way, the protocol supports psychiatrists faced with the complexities of assessing such requests, improves the quality of euthanasia practice by ensuring transparency and uniformity, and offers patients specialised support and guidance during their euthanasia procedure. Some concerns still remain (e.g., relating to possible unrealistic patient expectations and to the absence of aftercare for the bereaved or for patients whose requests have been refused). **Full text:** <http://bit.ly/2jVjpWQ>
- *GPNEWS* (Royal Australian College of General Practitioners) | Online – 4 September 2019 – **'Voluntary assisted dying: The current state of affairs.'** Legislation has passed Western Australia's lower house, bringing it one step closer to legalisation in the state. The Voluntary Assisted Dying Bill 2019 easily passed through the legislative assembly via a conscience vote 44-12, but is expected to face a more difficult passage through the upper house. If successful, Western Australia would become the second state in Australia to legalise voluntary assisted dying, after Victoria officially legalised the practice in June. The proposed bill differs slightly to Victoria's legislation, but would allow terminally ill patients likely to die within six months, or 12 months if living with a neurodegenerative condition, to access the scheme, provided they meet all the requirements. However, while voluntary assisted dying appears to have the support of the Western Australia community, critics ... are concerned about the standard of safeguards and the lack of a requirement for a psychiatric assessment. Western Australia is not alone in considering voluntary assisted dying legislation, with almost every state and territory across the country investigating its merits. **Full text:** <http://bit.ly/2lXUJxF>

N.B. Royal Australian College of General Practitioners' statement on voluntary assisted dying legislation:
Download/view at: <http://bit.ly/2YbfQLd>

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 3 September 2019 – **'U.S. hospice structure and its implications for the "right to die" debate.'** A goal of U.S. hospice care is to reduce the feeling of burden to others (FBO). But in America, hospice is limited in its ability to do so because of the high caregiver burden it places on family members of dying people. Through a historical study, the author shows that this burden was excessive when the hospice system was created and has worsened over time. Through three ethnographic vignettes, he demonstrates how this burden inculcates in dying people the FBO. The author examines the bioethical implications of this finding for the existing U.S. debate about physician-assisted suicide (PAS). The presence of FBO due to insufficient hospice care supports arguments made by PAS opponents about the social pressure placed on dying people. This finding is not itself sufficient to resolve the "right to die" debate. But it provides the ground for a compromise, across the debate, to reduce the FBO by changing U.S. hospice structure. The resulting consensus will further the goals of both PAS proponents and opponents. **Abstract:** <http://bit.ly/2lwCk19>

Cont.

- *MÉDECINE PALLIATIVE* | Online – 3 September 2019 – ‘**Euthanasia and paediatrics: Chosen death.**’ The author presents his own reflection about euthanasia in Belgium and the extension of it to children. Since 2002, under certain conditions an adult patient can apply to medical assistance to death called euthanasia. Since 2014, minors can take a similar step. Euthanasia is not just a lethal act. It is the conclusion of a long process of accompaniment and listening to the patient. The patient’s voice becomes preponderant: the law has allowed the patient to remain the subject and actor of his life, even when it is entering its terminal phase. It opens a space for discussion and preliminary information to allow the two protagonists, patient and doctor, to look for the best track to follow. In practice, euthanasia is an act that is the result of a transparent consultation between the patient and his/her doctor shared with the family and the healthcare team. **Abstract:** <http://bit.ly/2lwVltR>

N.B. French language article.

- *NURSING PHILOSOPHY* | Online – 2 September 2019 – ‘**Medical assistance in dying: A political issue for nurses and nursing in Canada.**’ In early 2015, the Supreme Court of Canada released its landmark decision *Carter v. Canada (Attorney General)*, which legalized physician-assisted suicide in particular clinical situations. The new law provided the broad national framework for medical assistance in dying (MAiD) in Canada but, once the law was passed, provincial and territorial governments and health professional regulatory bodies each had to undertake a process of developing policies, procedures and processes to guide MAiD-related practice specific to their jurisdiction. The authors examine the political ramifications and professional tensions arising from MAiD for nurses and nursing, focusing specifically upon the impacts for registered nurses. They identify how variations in the provincial and territorial literature and regulatory guidelines across Canada have given rise to role confusion and uncertainty among some registered nurses and how this may potentially impact patient care. The authors highlight the need for greater political activism among nurses to foster greater clarity in nursing roles in MAiD and to advocate for improved supports for patients and those close to them. **Abstract:** <http://bit.ly/2lYdT6z>

Publishing Matters

Perspectives from authors and editors in the biomedical disciplines on predatory journals: Survey study

JOURNAL OF MEDICAL INTERNET RESEARCH, 2019;21(8):e13769. Predatory journals fail to fulfill the tenets of biomedical publication: peer review, circulation, and access in perpetuity. Despite increasing attention in the lay and scientific press, no studies have directly assessed the perceptions of the authors or editors involved. Potential online predatory journals were randomly selected among 350 publishers and their 2,204 biomedical journals. Author and editor email information was valid for 2,227 total potential participants. A survey for authors and editors was created in an iterative fashion and distributed. A total of 249 complete survey responses were analyzed. A total of 40% of editors (17/43) surveyed were not aware that they were listed as an editor for the particular journal in question. A total of 21.8% of authors (45/206) confirmed a lack of peer review. Whereas 77% (33/43) of all surveyed editors were at least somewhat familiar with predatory journals, only 33.0% of authors (68/206) were somewhat familiar with them. Only 26.2% of authors (54/206) were aware of Beall’s list of predatory journals versus 49% (21/43) of editors. A total of 30.1% of authors (62/206) believed their publication was published in a predatory journal. After defining predatory publishing, 87.9% of authors (181/206) surveyed would not publish in the same journal in the future. Authors publishing in suspected predatory journals are alarmingly uninformed in terms of predatory journal quality and practices. Editors’ increased familiarity with predatory publishing did little to prevent their unwitting listing as editors. Some suspected predatory journals did provide services akin to open access publication. Education, research mentorship, and a realignment of research incentives may decrease the impact of predatory publishing. **Abstract:** <http://bit.ly/2UnnfWt>

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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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