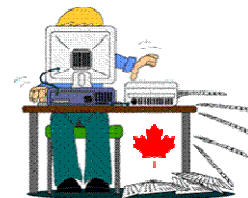


Media Watch...

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

Dissonance between values and actions: Scroll down to [Specialist Publications](#) and ‘Moral experiences of humanitarian health professionals caring for patients who are dying or likely to die in a humanitarian crisis’ (p.8), in *Journal of International Humanitarian Action*.

Canada

Island Health debuts program to help families cope with assisted dying

BRITISH COLUMBIA | *The Times-Colonist* (Vancouver) – 4 September 2018 – Island Health has responded to the issue of medically assisted death by creating an infrastructure that includes eighteen doctors and nurse practitioners trained in the procedure and more than 100 assessors involved in examining people to consider their eligibility. The organization is also approaching the issue from the perspective of friends and loved ones of those who have chosen a medically assisted death. The geographic area covered by Island Health, which includes Vancouver Island and mainland communities north of Powell River, has a relatively high number of medically assisted deaths – with 575 from June 2016 to 20 August of this year. <https://goo.gl/AnVyqi>

Specialist Publications

‘Patterns of care during the terminal hospital admission for patients with advanced heart failure: A retrospective cohort study’ (p.4), in *Canadian Journal of Cardiology*.

‘The emerging role of palliative care in the management of Canadians with heart failure’ (p.4), in *Canadian Journal of Cardiology*.

Journal Watch

‘How predatory journals leak into PubMed’ (p.12), in *Canadian Medical Association Journal*.

U.S.A.

New Jersey expands Medicaid coverage for end-of-life planning

NEW JERSEY | *NJ Spotlight* (Montclair) – 4 September 2018 – Hundreds of thousands of New Jersey residents could benefit from healthcare that better aligns with their final wishes – and help to curb growing medical costs over time – thanks to changes officials are making to the state’s Medicaid program. The

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Department of Human Services ... announced that they intend to extend Medicaid's coverage for advanced care planning: discussions led by physicians or other healthcare providers about the patient's final medical wishes and how they would like these carried out if they are unable to speak for themselves. The process can involve filling out documents known as advanced directives or Practitioner Orders for Life Sustaining Treatment forms, and frequently encompasses family members, loved ones, or surrogates; versions are available on the state Department of Health website. New Jersey officials are also working to develop an electronic system that allows these forms to be stored in a database accessible to hospitals and other providers throughout the state. <https://goo.gl/V5YsBA>

Specialist Publications

'Military culture: Working with veterans' (p.4), in *American Journal of Psychiatry*.

'A seat at the table: The positioning of families during care conferences in nursing homes' (p.6), in *The Gerontologist*.

'Use of inpatient palliative care services in patients with advanced cancer receiving critical care therapies' (p.9), in *Journal of the National Comprehensive Cancer Network*.

'National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition' (p.10), in *Journal of Palliative Medicine*.

Life in nursing homes and assisted living means waking to a neighbor's death

THE WASHINGTON POST | Online – 3 September 2018 – Death and its companion, grief, have a profound presence in long-term-care (LTC) facilities. Residents may wake up one morning to find someone they saw every day in the dining room gone. Nursing aides may arrive at work to find an empty bed, occupied the day before by someone they'd helped for months. But the tides of emotion that ripple through these institutions are rarely acknowledged openly. "LTC administrators view death as something that might upset residents," said physician Toni Miles, a professor of epidemiology and biostatistics at the University of Georgia. "So when someone passes away, doors are closed and the body is wheeled discreetly out the back on a gurney. It's like that person never existed." Miles wants to see bereavement freely recognized to end what she calls "the silence surrounding loss and death in LTC." Fraught reactions to loss and death are common among nursing assistants and other staff members in LTC facilities, research shows.¹ When feelings aren't acknowledged, grief can lead to a host of physical and psychological symptoms, including depression, distancing and burnout. <https://goo.gl/s4uegr>

1. 'Grief after patient death: Direct care staff in nursing homes and homecare,' *Journal of Pain & Symptom Management*, published online 3 July 2014. [Noted in the 7 July 2014 issue of *Media Watch* (#365, p.10)] **Full text (via PubMed):** <https://goo.gl/4MFPSy>

Noted in *Media Watch* 12 June 2017 (#516, p.9):

- *JOURNAL OF CANADIAN STUDIES*, 2017;50(2):396-421. '**Intensifying relational care: The challenge of dying in long-term residential care.**' Although the culture change movement has sought to transform residential care facilities from *warehouses of death* into homes for living, there is growing recognition of the need to address dying within these settings. Drawing on data from an international and interdisciplinary study, the authors explore the state of end-of-life care in residential care facilities, identifying barriers to the provision of compassionate care for the dying, as well as promising practices and areas for future inquiry. **Abstract (w. link to references):** <https://goo.gl/f37VGM>

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://goo.gl/5CHoAG>



International

Students fill in gap in palliative care services in Glasgow

U.K. (Scotland) | Glasgow Live – 7 September 2018 – An award-winning course designed and delivered by Glasgow Clyde College is helping to fill a gap in palliative care (PC) provision in the Glasgow community. Research provided by the PV team at Queen Elizabeth University Hospital Trust indicates 25% of PC patients in Glasgow without a cancer diagnosis are unable to access the service, a figure that has grown from the 20% reported 18 months ago. Responding to the gap, Glasgow Clyde College developed the unique Complementary Therapies for Clinical Practice course, enabling qualified complementary and beauty therapists to deliver therapies safely for people with life-limiting conditions. The course was recently recognised as the winner of the contribution to the local community award at the Herald Higher Education Awards. Collaborating with healthcare providers throughout Greater Glasgow, the course also provides therapists with the skills and professional competence to work confidently within a healthcare environment alongside healthcare professionals. <https://goo.gl/gJRkBT>

End-of-life care in Korea

More medical institutions involved in hospice sector

SOUTH KOREA | *The Korea Bizwire* (Seoul) – 3 September 2018 – Starting this month, the government is expanding a trial run of allowing more medical institutions to join the hospice industry. According to the Ministry of Health & Welfare and the Health Insurance Review & Assessment Service, 14 new hospice institutions providing either home or consultation hospice services were given access to the national health insurance system. As such, there are now 33 institutions that offer home-type hospice services and 25 offering consultation-type hospice services. The Health Ministry has been pushing recently for more medical institutions to join the hospice industry in order to improve the quality of life of terminally ill patients and their families. A total of 25 medical institutions have been offering home-type hospice services since March of 2016. <https://goo.gl/3UYJJe>

Noted in Media Watch 5 February 2018 (#549, p.8):

- SOUTH KOREA | *The Korea Bizwire* (Seoul) – 31 January 2018 – **‘More terminal cancer patients turn to home hospice services in Korea.’** More than 1,000 terminal cancer patients took advantage of home hospice services during a trial period between March 2016 and last July 2017. The government began allowing home hospice services for terminally ill patients after launching a pilot program in March 2016, offering assistance to those who suffer from terminal cancer, AIDS, chronic liver cirrhosis, and chronic obstructive pulmonary disease. <https://goo.gl/XD3VKS>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Queensland) | ABC News (Brisbane) – 2 September 2018 – **‘Voluntary euthanasia inquiry announced in Queensland, issue must be confronted Premier says.’** Queensland’s Premier has ordered an inquiry into end-of-life care, including the issue of voluntary euthanasia, with Queensland the last state in the country to debate the issue. Annastacia Palaszczuk has told the Labor Party Conference in Brisbane the issue must be confronted. She said the parliamentary health committee would lead the examination, which will also look at aged care and palliative care. Ms. Palaszczuk said the inquiry would also look at the broader issue of the cost and complexity of aged care in Queensland. <https://goo.gl/NaTRrt>

Specialist Publications

Military culture: Working with veterans

AMERICAN JOURNAL OF PSYCHIATRY | Online – 1 September 2018 – According to the U.S. Department of Veterans Affairs (VA), around 70% of physicians in the U.S. have received some of their training with the VA. A total of 178 of 183 U.S. medical schools are affiliated with the VA, and 43,565 medical residents, 24,683 medical students, and 463 advanced fellows received some or all of their clinical training within the VA system in 2017. Despite this training, most clinicians do not feel adequately prepared to provide high-quality care for veterans. In a recent study, only 13% of mental health providers met readiness criteria for culture competency in treating veterans. **Full text:** <https://goo.gl/9mQICS>

Noted in Media Watch 18 December 2017 (#543, p.5):

- U.S. (California) | *California Healthline* (Oakland) – 11 December 2017 – **‘Reverberations from war complicate Vietnam veterans’ end-of-life care.’** For some veterans, the stoicism honed on the battlefield often returns full-force as they confront a new battlefield in the hospital, making them less willing to admit they are afraid or in pain, and less willing to accept treatment. Other vets, with post-traumatic stress disorder, are even more reluctant to take pain-relieving opioids because the drugs can actually make their symptoms worse, triggering frightening flashbacks. <https://goo.gl/uYpZhb>

Noted in Media Watch 2 October 2017 (#532, p.10):

- *HOME HEALTHCARE NOW*, 2017;35(9):485-493. **‘End-of-life care for World War II, Korea, and Vietnam-era veterans.’** Highlighted in this article are a variety of ways in which home care and hospice clinicians and agencies can honor and respect veterans. Listening to a patient reminisce and observing for potential complications can facilitate the clinician in seeking the right care or support for the patient, their families, and their caregivers. Asking the patient, their families, and caregivers what their wishes are is important to providing patient-centered care. **Full text:** <https://goo.gl/FKEL2b>

Patterns of care during the terminal hospital admission for patients with advanced heart failure: A retrospective cohort study

CANADIAN JOURNAL OF CARDIOLOGY, 2018;34(9):1215-1218. Costs of end of life (EoL) care for patients who have advanced heart failure (HF) are increasing. There is a perception that many of these patients receive aggressive treatments near the EoL. However, actual patterns of care are unclear. The authors describe the use of life-sustaining treatments and the timing of goals of care discussions during patients’ terminal admission for HF. The authors identify 133 eligible decedents of whom 67 (50%) received some form of life-sustaining treatment, although only 14 (11%) received cardiopulmonary resuscitation (CPR). The first documented orders for scope of treatment were: CPR for 39 (29%), active medical treatment with no CPR for 81 (61%), and comfort care with no CPR for 11 (8%) patients. The last documented orders were for comfort care in 85 (64%) patients. There were 28 (21%) patients who received palliative care (PC) consultation. Median time between PC consultation and death was 6 days and between orders for comfort care and death was 24 hours. In contrast to the high mortality risk of this study cohort, PC consultation was often absent or in the final days of life, with orders for comfort-oriented care being written only 24 hours before death... **Abstract (w. link to references):** <https://goo.gl/piQmNZ>

Related

- *CANADIAN JOURNAL OF CARDIOLOGY*, 2018;34(9):1114-1115. **‘The emerging role of palliative care in the management of Canadians with heart failure.’** There are currently more than 600,000 Canadians living with heart failure (HF), with an additional 50,000 being diagnosed yearly. Although the management of HF has progressed rapidly in recent decades, the 5-year mortality rate continues to be approximately 50%. Many patients with HF experience a high symptom burden. The most frequently reported symptoms are dyspnea, pain, fatigue, and comorbid depression, all of which can adversely impact quality of life. The optimal timing of when to introduce PC in a patient’s illness trajectory remains less clear. **Full text:** <https://goo.gl/VbN4vz>

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- *JOURNAL OF CARDIOVASCULAR NURSING* | Online – 28 August 2018 – ‘**Inadequate communication exacerbates the support needs of current and bereaved caregivers in advanced heart failure and impedes shared decision-making.**’ The central feature of the caregivers’ experience was identified as being “a physical and emotional rollercoaster.” There were 3 main themes identified: 1) Poor communication; 2) Living with uncertainty; and, 3) Lack of service provision. These themes were supported by 6 subthemes: 1) Inadequate understanding of palliative care; 2) A 24/7 physical burden; 3) Emotional burden; 4) Inability to plan; 5) No care continuity; and, 6) Dying lonely and unsupported. **Abstract:** <https://goo.gl/nmkNJG>

N.B. Additional articles: on PC in heart failure noted in the 3 September 2018 issue of Media Watch (#579, p.8).

Delivering pediatric palliative care: From denial, palliphobia, pallilalia to palliative

CHILDREN | Online – 31 August 2018 – Among the over 21 million children with life-limiting conditions worldwide that would benefit annually from a pediatric palliative care (PPC) approach, more than eight million would need specialized PPC services. In the U.S. alone, more than 42,000 children die every year, half of them infants younger than one year. Advanced interdisciplinary 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. Data reveals the majority of distressing symptoms in children with serious illness (such as pain, dyspnea and nausea/vomiting) were not addressed during their end-of-life period, and when treated, therapy was commonly ineffective. Whenever possible, treatment should focus on continued efforts to control the underlying illness. At the same time, children and their families should have access to interdisciplinary care aimed at promoting optimal physical, psychological and spiritual wellbeing. Persistent myths and misconceptions have led to inadequate symptom control in children with life-limiting diseases. PPC advocates the provision of comfort care, pain, and symptom management concurrently with disease-directed treatments. Families no longer have to opt for one over the other. They can pursue both, and include integrative care to maximize the child’s

quality of life. Since most of the sickest children with serious illness are being taken care of in a hospital, every children’s hospital is now expected to offer an interdisciplinary palliative care service as the standard of care. The authors address common myths and misconceptions which may pose clinical obstacles to effective PPC delivery and discusses the four typical stages of PPC program implementation. **Full text:** <https://goo.gl/rvFUJ8>

Extract

When implementing a pediatric palliative care (PPC) service, the development often goes through four steps in their development. These should be anticipated, and an action plan might include:

Denial: Document unmet needs, undertake surveys among staff, patients and providers

Palliphobia: Close collaboration with colleagues; disciplined planning, rapid conflict resolution

Pallilalia: Documentation of PPC value to leadership; grand rounds by expert in field and external review

Palliative: “Do good & talk about it,” perform QI, evaluate value of PPC in accountable care organization/bundled payments environment; include clinical and administrative innovators in program development

Secure funding: “Make sure your passion is connected with somebody’s payment system”

The role of palliative care in oral cavity carcinoma

CURRENT OTORHINOLARYNGOLOGY REPORTS | Online – 5 September 2018 – Palliative care (PC) for patients with oral cavity carcinoma (OCC) has traditionally been reserved for patients with advanced disease, recurrent disease, or poor performance status who are unable to undergo surgical or adjuvant treatments. Patients with early- or mid-stage disease were not typically offered palliative services. However, patients at all stages face quality of life issues including disruption of speech, eating, pain, mood, self-image, social interactions, work, and daily activities. This can directly affect performance status and has been shown to increase length of hospitalizations and decrease overall survival. Recent evidence suggests that involving PC earlier may decrease rates of depression, decrease cost, improve communication, and increase overall survival outcomes. Furthermore, new applications and innovations in radiation therapy, immunotherapy, and chemotherapy have broadened the palliative therapies available to patients with incurable disease. **Abstract (inc. list of references):** <https://goo.gl/Z9t86p>

The “surprise question” in neuro-rehabilitation: Prognosis estimation by neurologist and palliative care physician: A longitudinal, prospective, observational study

FRONTIERS IN NEUROLOGY | Online – 3 September 2018 – The 12-months “surprise question” (12-SQ) for estimating prognosis and the need for integrating palliative care (PC) services has not yet been investigated for neurological patients (NP). Of 634 patients [i.e., study participants], 279 (44%) patients ... (or, alternatively, their legal representative) consented and were assessed at baseline. Per patient NP and PC physician both answered the 12-SQ with “Yes” (164), with “No” (42), or had different opinions (73). The “No” group displayed the highest symptom burden on all three measures for both disciplines. Overall, PC physicians scored higher (i.e., worse) than NP on all measures used. Combining the 12-SQ with a measurement assessing PC and neurological issues could potentially improve the 12-SQ’s predictive performance of twelve-month survival and help to identify when to initiate the PC approach. Clinical experiences influence assessment and prognosis estimation. **Abstract:** <https://goo.gl/TtWjzB>

N.B. Additional articles on the “surprise question” noted in the 23 April 2018 issue of Media Watch (#560, p.8).

A seat at the table: The positioning of families during care conferences in nursing homes

THE GERONTOLOGIST | Online – 29 August 2018 – Current nursing home policy emphasizes the need for collaborative, team-based care planning in which families and/or residents are actively involved. Resident care conferences are common where care providers, families, and/or residents discuss and coordinate resident care needs and evaluate care goals. This study critically examines the process, structure, and content of care conferences to expand our understanding of how resident care is negotiated among care providers and families in this context. Thirty-seven care conferences were observed. Field notes and interview data were thematically analyzed with a focus on what was said, who said what and to whom, whose voice was privileged, and how power manifested between care providers, families, and/or residents. The use of predetermined agendas and processes, clinically generic reporting, and technical jargon reproduced the structural inequality between care providers and families making collaboration difficult to effectively negotiate. For care conferences to meaningfully contribute to person-centered care, it is imperative that mutual exchange be promoted and families empowered to participate as equals. **Abstract:** <https://goo.gl/PHrwXR>

N.B. Additional articles on family conferences in the context of palliative and end-of-life care noted in the 12 February 2018 issue of Media Watch (#550, p.13).

End-of-life care in the U.K.

A population-based conceptual framework for evaluating the role of healthcare services in place of death

HEALTHCARE | Online – 30 August 2018 – There is a significant geographical disparity in place of death. Socio-demographic and disease-related variables only explain less than a quarter of the variation. Healthcare service factors may account for some (or much) of the remaining variation, but their effects have never been systematically evaluated, partly due to the lack of a conceptual framework. The framework [detailed by the authors] conceptualizes the impact of healthcare services on the place of death as starting from the end-of-life care (EoLC) policies that in turn influence service commissioning and shape healthcare service characteristics, including service type, service capacity – facilities, service location, and workforce, through which service utilization and ultimately place of death are affected. Patient socio-demographics, disease-related variables, family and community support and social care also influence place of death, but they are not the focus of this framework and therefore are grouped as needs and other environmental factors. Information on service utilization, together with the place of death, creates loop feedback to inform policy and service commission. The framework provides guidance for analysis aiming to understand the role of healthcare services in place of death. It aids the interpretation of results in the light of existing knowledge and potentially identifies service factors that can be addressed to improve EoLC. **Abstract:** <https://goo.gl/dZQMTT>

Family members' experiences of the end-of-life care environments in acute care settings: A photo-elicitation study

INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH & WELL-BEING | Online – 3 September 2018 – This article explores experiences of the acute-care environment as a setting for end-of-life (EoL) care from the perspective of family members of a dying person. The authors used participant-produced photographs in conjunction with follow-up interviews with nine family members to persons at the EoL, cared for in two acute-care settings. The analysis process resulted in three constructed themes: 1) Aesthetic and un-aesthetic impressions; 2) Space for privacy and social relationships; and, 3) Need for guidance in crucial times. Aspects of importance in the physical setting related to aesthetics, particularly in regard to sensory experience, and to a need for enough privacy to facilitate the maintenance of social relationships. Interactions between the world of family members and that of professionals were described as intrinsically related to guidance about both the material and immaterial environment at crucial times. **Abstract (w. link to references):** <https://goo.gl/SzonzD>

Ambiguity in end-of-life care terminology: What do we mean by “comfort care”?

JAMA INTERNAL MEDICINE | Online – 4 September 2018 – “Don't you think he looks comfortable right now?” We stand quietly at the foot of the bed and watch. The patient lies semisupine in the mechanical bed, intermittently breathing slowly and deeply before longer apneic pauses. Despite the soft groan of the bilevel positive airway pressure machine and the occasional chirps from four continuous intravenous drips, he seems settled, arms open, hands unfolded to the fluorescent overhead lighting. Even in this state of unconsciousness, he seems to be preparing to die. **First page view:** <https://goo.gl/ww4NDW>

Noted in Media Watch 23 April 2018 (#560, p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 20 April 2018 – ‘**Effects of using “palliative,” “supportive,” or “hospice” care terminology.**’ In this study, the terminology used had a large effect and, compared with alternatives, the information labeled as being about “supportive” care was significantly more likely to be selected. There may be low-cost, highly feasible changes in language choice that increase the dissemination of relevant health information. **Abstract:** <https://goo.gl/1mWwno>

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Noted in Media Watch 1 July 2013 (#312, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 June 2013 – **Concepts and definitions for “actively dying,” “end of life,” “terminally ill,” “terminal care” and “transition of care”:** **A systematic review.** The authors’ findings highlight the urgent need to develop consensus definitions for these terms to facilitate daily communications related to clinical care, scientific research, education, and public policy. **Full text:** <https://goo.gl/pK7t5Y>

Noted in Media Watch 3 September 2012 (#269, p.7):

- *SUPPORTIVE CARE IN CANCER* | Online – 31 August 2012 – **‘Concepts and definitions for “supportive care,” “best supportive care,” “palliative care,” and “hospice care” in the published literature, dictionaries, and textbooks.’** Commonly used terms such as “supportive care,” “best supportive care,” “palliative care,” and “hospice care” were rarely and inconsistently defined in the palliative oncology literature. **Abstract (inc. list of references):** <https://goo.gl/2TE8PL>

N.B. Additional articles on terminology in the context of end-of-life care noted in the 5 October 2015 issue of Media Watch (#430, pp.15-16).

What matters to persons with dementia at the end of life: Perspectives of proxy decision makers

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2018;20(5):478-485. For substituted decision makers for the growing number of persons with dementia (PWDs), understanding the PWD’s values is a prerequisite for making end-of-life (EoL) decisions congruent with the PWD’s wishes. This qualitative study explored PWD health care proxies’ perspectives on values that are important to PWDs at EoL and challenges in making EoL decisions that reflect PWDs’ values. Semistructured interviews were conducted with 20 PWD proxies, and data were analyzed using the content analysis, an inductive approach to identify themes. Three main themes emerged: 1) What matters to PWDs at EoL; 2) Uncertainty about the PWD’s current wishes and EoL trajectory poses challenges; and, 3) The role of health care professionals’ empathic and clear communication. Together, these findings suggest proxies’ efforts to understand and respect PWDs’ wishes at EoL and communication strategies health care providers can use to help PWD proxies cope with uncertainty and challenges in EoL decision making. **Abstract:** <https://goo.gl/Dkfwjb>

N.B. Selected articles on decision making for people living with dementia noted in the 27 August 2018 issue of Media Watch (#578, p.9).

Moral experiences of humanitarian health professionals caring for patients who are dying or likely to die in a humanitarian crisis

JOURNAL OF INTERNATIONAL HUMANITARIAN ACTION | Online – 3 September 2018 – Wars, disasters, and epidemics affect millions of individuals every year. International non-governmental organizations respond to many of these crises and provide healthcare in settings ranging from a field hospital deployed after an earthquake, to a health clinic in a longstanding refugee camp, to a treatment center during an infectious disease outbreak. The primary focus of these activities is to save lives. However, inevitably, many patients cannot be saved. The authors undertook an interpretive description study to investigate humanitarian policy-maker and care providers’ experiences and perceptions of palliative care during humanitarian crises. They report on interviews with 23 health professionals, 11 of whom also had experience as policy-makers within a humanitarian organization. The authors use the concept of moral experience as an analytic lens: participants’ experiences of values that they held to be important being realized or thwarted as they responded to the needs of patients who were dying or likely to die. Five themes related to participants’ moral experiences were identified, all of which relate to values of compassion in the provision of care, and justice in accessing it: 1) Participants described intervening to ease the suffering of dying patients as an inherent aspect of humanitarianism and their duty as health professionals; 2) Participants also expressed that upholding dignity was of critical importance, stemming from a recognition of shared humanity and as an act of respect; 3) Since humanitarian action is provided in situations of scar-

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city, prioritization is inescapable. (Acknowledging the primacy of curative care in emergencies, participants also emphasized the importance of ensuring that care for the dying was attended to, including during triage); 4) Participants reported working within and pushing against systemic constraints such as legal or logistical barriers to opioids, lack of guidelines, and conflicting views with colleagues; and, 5) Given the stakes involved, participants felt a heavy weight of responsibility and described their challenges in carrying it. These findings illuminate experiences responding to patients who are dying or likely to die, and how these connect with the values of humanitarian health professionals, sometimes resulting in dissonance between values and actions. They also point to the need to make more space for palliative, alongside curative, approaches to care in situations of humanitarian crises, ideally by further integrating them. **Full text:** <https://goo.gl/i6EiYb>

Use of inpatient palliative care services in patients with advanced cancer receiving critical care therapies

JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK, 2018;16(9):1055-1064. Invasive mechanical ventilation (IMV), dialysis for acute kidney failure, and other critical care therapies (CCTs) are associated with a high risk for complications in patients with metastatic cancer. Inpatient palliative care (IPC) can assist in assessing patients' preferences for life-prolonging treatment at the end of life. This study investigated the use pattern of IPC, outcomes (in-hospital mortality, length of stay [LoS], discharge destination, and cost of care), and predictors of IPC use in patients with metastatic cancer who received CCTs. The authors hypothesized that IPC services are underused in this cohort. In this retrospective cohort study, they used the 2010 California State Inpatient Databases to identify adults with metastatic cancer who received CCTs that are common and reliably coded (IMV, tracheostomy, percutaneous endoscopic gastrostomy tube, dialysis for acute kidney failure, and total parenteral nutrition). We determined IPC use in all patients, in those who received IMV, and across 4 cancer subtypes (lung, breast, colorectal, and genitourinary). The authors identified 5,862 hospitalizations, 19.8% of which used IPC services. IPC use varied across cancer subtypes... Patients who received and did not receive IPC services had high in-hospital mortality rates (63.9% and 29.8%, respectively), and costs of care and LoS were lower in survivors who received IPC compared with those who did not. Predictors of IPC use were lung cancer (vs colorectal or genitourinary cancer), higher co-morbidity score, do-not-

resuscitate status on admission or within 24 hours of admission, infections (vs cancer-related diagnoses), and higher hospital bed count. Use of IPC was low in the cohort who received CCTs with poor outcomes, although data on outpatient palliative care services is lacking. **Abstract:** <https://goo.gl/6B7FJF>

Terminal withdrawal of mechanical ventilation: A hospice perspective for the intensivist

JOURNAL OF INTENSIVE CARE MEDICINE | Online – 6 September 2018 – The intensive care unit (ICU) and hospice inpatient unit (IPU) environments differ in many ways. Although both endeavor to provide the best care possible for their patients, the day-to-day goals of these environments are almost antithetical. Similarly, the experiences and expertise of the staff differ. When performing a similar clinical task, it may be addressed in different ways because each group is engrained in their primary day-to-day focus. Terminal withdrawal of mechanical ventilation is a procedure that is performed in both ICUs and some hospice IPUs. Previous examinations of this subject have been based largely upon the correlative background, practices, and perceptions of the ICU prescriber. The purpose of this review is to examine how the manner in which this procedure is performed in the hospice environment may differ in ways that the intensivist can incorporate into their own plan of care, or better appreciate when making the decision to remove mechanical ventilation in the critical care unit or transfer the patient to a hospice environment for the procedure to be completed. **Abstract:** <https://goo.gl/wrxXQa>



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 beginning on p.13.

National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines, 4th Edition

JOURNAL OF PALLIATIVE MEDICINE | Online – 4 September 2018 –

The goal of the Guidelines is to improve access to quality palliative care (PC) for all people with serious illness regardless of setting, diagnosis, prognosis, or age. They are intended to encourage and guide healthcare organizations and clinicians (including non-palliative care specialists) across the care continuum to integrate PC principles and best practices into their routine assessment and care of all seriously ill patients and their family caregivers. The Guidelines formalize and delineate evidence-based processes and practices for the provision of safe and reliable high-quality PC for adults, children, and families with serious illness in all care settings. This article presents the key domains and guidelines of the 4th edition.



Abstract: <https://goo.gl/VBC8fv>

The key challenges of discussing end-of-life stroke care with patients and families: A mixed-methods electronic survey of hospital and community healthcare professionals

JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS OF EDINBURGH, 2018;48(3):217-224. Communication between professionals, patients and families about palliative and end-of-life care after stroke is complex and there is a need for educational resources in this area. 599 healthcare professionals responded to an electronic survey. Educational topics that were either definitely or probably needed were: ensuring consistent messages to families and patients (88%); resolving conflicts among family members (83%); handling unrealistic expectations (88%); involving families in discussions without them feeling responsible for decisions (82%); discussion of prognostic uncertainties (79%); likely mode of death (72%); and oral feeding for 'comfort' in patients at risk of aspiration (71%). Key topics of unmet need for education in end-of-life care in stroke have been identified and these have influenced the content of an open access, web-based educational resource. **Abstract (via PubMed):** <https://goo.gl/jCkBeq>

N.B. Click on link to the journal to access pdf of the full text.

Noted in Media Watch 12 March 2018 (#554, p.8):

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2018;190(9):E238-E246. '**Outcomes, experiences and palliative care in major stroke: A multicentre, mixed-method, longitudinal study.**' The authors describe the experiences and needs of patients and caregivers, and explore whether and how palliative care should be integrated into stroke care. **Full text:** <https://goo.gl/dP8Ht4>

Noted in Media Watch 11 December 2017 (#542, p.14):

- *NEUROLOGY TODAY*, 2017;17(23):14-15. '**What accounts for disparities in the use of palliative stroke care? It may not be what you think.**' A new analysis suggests it might be the systems in place in hospitals serving minority populations – and not the belief systems of individual patients – that account for racial disparities in care.¹ **Full text of expert commentary:** <https://goo.gl/SX82Md>

1. 'Racial differences in palliative care use after stroke in majority-white, minority-serving, and racially integrated U.S. hospitals,' *Critical Care Medicine*, 2017;45(12):2046-2054. **Abstract:** <https://goo.gl/NujFLJ>

The effect of natural disasters on cancer care: A systematic review

THE LANCET ONCOLOGY | Online – 1 September 2018 – As the incidence of cancer and the frequency of extreme weather events rise, disaster mitigation is becoming increasingly relevant to oncology care. In this systematic Review, the authors aimed to investigate the effect of natural disasters on cancer care and the associated health effects on patients with cancer. Of the 4,593 studies identified, only 85 articles met all the authors' eligibility criteria. Damage to infrastructure, communication systems and medication,

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and medical record losses substantially disrupt oncology care. The effect of extreme weather events on survival outcomes is limited to only a small number of studies, often with inadequate follow-up periods. To the best of the authors' knowledge, this is the first systematic review to assess the existing evidence base on the health effects of natural disaster events on cancer care. They advocate for the consideration of patients with cancer during disaster planning. **Summary:** <https://goo.gl/epxKPA>

N.B. Additional articles on the provision of palliative care during humanitarian crises or natural disasters noted in the 20 August 2018 issue of Media Watch (#577, p.12).

Navigating the intangible: Working with non-physical suffering on the front lines of palliative care

OMEGA – JOURNAL OF DEATH & DYING | Online – 5 September 2018 – While relieving suffering is palliative care's primary aim, how palliative care (PC) providers navigate patients' non-physical suffering in their day-to-day work and the impact of working with non-physical suffering on the clinician have been understudied. Results of this study revealed that PC clinicians face several challenges in their efforts to navigate patients' non-physical suffering in their day-to-day work, including: 1) The intangible nature of non-physical suffering; 2) Systemic barriers (e.g., lack of time and adequate resources); 3) Clinician helplessness or suffering; and, 4) A lack of education, training, and support for clinicians specific to their work with patients' non-physical suffering. Study outcomes have the potential to improve frontline clinical care with patients and support and education for clinicians. **Abstract:** <https://goo.gl/rnVVv5>

Training for awareness of one's own spirituality: A key factor in overcoming barriers to the provision of spiritual care to advanced cancer patients by doctors and nurses

PALLIATIVE & SUPPORTIVE CARE | Online – 6 September 2018 – When patients feel spiritually supported by staff, we find increased use of hospice and reduced use of aggressive treatments at end of life, yet substantial barriers to staff spiritual care provision still exist. The authors aimed to study these barriers in a new cultural context and analyzed a new subgroup with “unrealized potential” for improved spiritual care provision: those who are positively inclined toward spiritual care yet do not themselves provide it. There were 770 respondents (40% physicians, 60% nurses) from 14 Middle Eastern countries. The results showed that 82% of respondents think staff should provide spiritual care at least occasionally, but 44% provide spiritual care less often than they think they should. In multivariable analysis of respondents who valued spiritual care yet did not themselves provide it to their most recent patients, predictors included low personal sense of being spiritual and not having received training. How “developed” a country is negatively predicted spiritual care provision. Self-perceived barriers were quite similar across cultures. Significance of results Despite relatively high levels of spiritual care provision, the authors observed a gap between desirability and actual provision. Seeing oneself as not spiritual or only slightly spiritual is a key factor demonstrably associated with not providing spiritual care. Efforts to increase spiritual care provision should target those in favor of spiritual care provision, promoting training that helps participants consider their own spirituality and the role that it plays in their personal and professional lives. **Abstract (inc. references):** <https://goo.gl/XoaXYa>



Discussing death: Making end of life implicit or explicit in paediatric palliative care consultations

PATIENT EDUCATION & COUNSELING | Online – 31 August 2018 – Many clinicians and researchers advocate explicitly discussing death. There are, however, few studies of real-world conversations about death. Nine naturally occurring paediatric palliative care consultations were video recorded and analysed using conversation analytic methods. Focusing on three consultations in which end of life (EoL) was treated as a certain outcome, analysis explored ways in which EoL was made either implicit or explicit within these consultations. Analysis suggests that EoL was made explicit when: 1) Ancillary to the current focus of discussion; 2) In relation to someone else's child; or 3) Specifically relevant to the local context of the discussion. More commonly, in all other instances in the data, EoL was made implicit during discussions relating to this matter. **Abstract (w. link to references):** <https://goo.gl/Z4jaGx>

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Noted in Media Watch 13 March 2017 (#503, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 March 2017 – ‘**Affording opportunities to discuss deterioration in paediatric palliative care consultations:** This study identified two communicative practices used by a paediatric palliative care specialist that afforded opportunities to discuss deterioration: 1) Soliciting the family’s agenda for the consultation; and, 2) Initiating and maintaining topics where discussing deterioration is a relevant possibility. A common feature was indirect initiation of discussions about deterioration ...making such discussions possible, but without mandating or even suggesting that such discussion must occur. **Abstract:** <https://goo.gl/tY8cPW>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *AMERICAN JOURNAL OF PSYCHIATRY* | Online – 1 September 2018 – ‘**Is euthanasia psychiatric treatment? The struggle with death on request in The Netherlands.**’ Euthanasia motivated by psychiatric disorders has been legal in The Netherlands since 2002. To date, the number of granted requests is limited, but rising public awareness increases annually the number of requests. There still is controversy about the role of euthanasia in psychiatry and its practical implementations. The debate exceeds medical decision making and is primarily based on ethical and philosophical grounds. Eventually, the position of an individual psychiatrist toward euthanasia and caring for life depends on his or her metaphysical perspective on death. Is death solely the end of life, or is death the start of a meaningful life? Whatever stance one takes in the euthanasia debate, albeit good or bad, right or wrong, in the end, there is a terminal effect. Euthanasia for psychiatric disorders is an infinite debate with finite consequences. **Full text:** <https://goo.gl/sGsFWt>
- *GENERAL HOSPITAL PSYCHIATRY* | Online – 31 August 2018 – ‘**Consultation-liaison psychiatry and physician-assisted death.**’ The medical assistance in dying (MAiD) team [at the University Health Network Centre for Mental Health, at the University of Toronto] has managed 186 MAiD inquiries, assessed 95 MAiD requests and provided 49 MAiD interventions over a 24 month period. The two co-leaders of the MAiD team, 8 assessors and one intervention physician are consultation-liaison (C-L) psychiatrists. Each of the MAiD criteria – grievous medical condition, advanced state of irreversible decline, intolerable suffering, natural death reasonably foreseeable, voluntary request, capacity and informed consent – pose specific challenges to be resolved in assessment. The authors discuss several unique MAiD issues, including the role of education and mandatory psychiatric assessment and protocols. The MAiD team’s experience shows that C-L psychiatrists are well-situated to provide vital expertise and leadership to multispecialty physician assisted death teams. **Abstract:** <https://goo.gl/KNtiGs>

Journal Watch

How predatory journals leak into PubMed

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2018;190(35):E1042-E1045. Recent reports that PubMed, one of the world’s leading biomedical databases, includes predatory journals and their publications is cause for concern. PubMed handles millions of queries daily and represents a key source of knowledge for health researchers worldwide. Much medical research that underpins clinical practice relies on the findings generated by peer-reviewed studies that are retrieved via biomedical databases, in particular, those that are free to search such as MEDLINE and PubMed. Thus, it is imperative that these databases are free of contamination by the outputs of predatory journals with their critically flawed peer review procedures. The authors analyze why this is happening and identify some possible solutions to stop the penetration of predatory journals and publishers into biomedical databases. **Access options:** <https://goo.gl/2qVaDv>



Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

Distribution

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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.

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International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/fJczV6>

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PALLIATIVE CARE NETWORK: <https://goo.gl/YBP2LZ>

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[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at <https://goo.gl/6vdk9v>]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/ZRngsv>

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

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Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>

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

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>

[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <https://goo.gl/IOSNC7>

Europe

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U.K. | Omega, the National Association for End-of-Life Care: <http://goo.gl/UfSZtu>

South America



Academia Nacional de Cuidados Paliativos (Brazil): <https://goo.gl/b5CV31>



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net