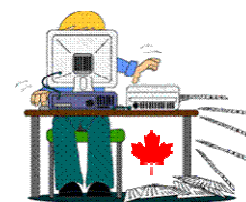


Media Watch...

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

Skillful branding and messaging of service innovation initiatives can help to overcome the emotional and attitudinal barriers restricting the use of current service lines, changing the focus of care for seriously-ill people from the hospital to their homes.

'For service innovation in end-of-life care, branding and messaging matter'
(p.6), in *Academy of Marketing Sciences Review*.

Canada

Bedlam over beds: We can no longer ignore our long-term care crisis

THE GLOBE & MAIL | Online – 28 May 2019 – Bedlam. That is the perfect descriptor of the state of long-term care (LTC) in Canada today. The bulge of aging baby boomers, combined with head-in-the-sand planning and a lack of investment in care homes has resulted in mind-boggling wait lists, crumbling infrastructure and catastrophic staffing shortages. And it's only going to get worse. A new report ... offers up a sobering summary of the current state of affairs.¹ For example, British Columbia is 3,000 beds short of current demand, although officially there are 1,379 people on wait lists, 340 of whom are living in hospitals because there is nowhere else to go. The province needs to build about 45,000 new beds – 2,250 a year – over the next 20 years (for context, it currently has 27,000). To staff those beds, 19,000 new health workers will be needed, including 13,000 personal support workers and 4,000 nurses. Yet, in the past two years, only one new facility has been approved in the province, with 120 beds. The situation is as bad, or worse, in every other jurisdiction; B.C. is doing relatively well. In Ontario, for example,

the wait list for LTC is a staggering 34,000 people. In Nova Scotia, one-third of hospital beds are occupied by "alternate level of care" (ALC) patients who have been discharged but cannot find a spot in LTC. Nationwide, there are 7,550 ALC patients – the equivalent of 25 hospitals with 300 beds each – the No. 1 driver of hallway medicine. The Canadian Association of Long Term Care estimates that 42,000 new beds are needed by 2023.² Yet, since 2005, the number of LTC homes in Canada has actually diminished, and so have the number of beds. <http://bit.ly/2Way6Hp>

Specialist Publications

'Educational needs of healthcare professionals and members of the general public in Alberta, Canada, 2 years after the implementation of medical assistance in dying' (p.12), in *Health & Social Care in the Community*.

Cont.

1. 'Bedlam in B.C.'s Continuing Care Sector,' BC Care Providers Association, May 2019. **Download/view at:** <http://bit.ly/2HFAL38>
2. 'Long Overdue: Improving Seniors Care in Canada,' Canadian Association of Long Term Care, November 2018. **Download/view at:** <http://bit.ly/2W8no4s>

Noted in Media Watch 21 January 2019 (#598, p.5):

- *AGEING & SOCIETY* | Online – 15 January 2019 – '**Mind the gap: Is the Canadian long-term care workforce ready for a palliative care mandate?**' The average expected lifespan in Canadian long-term care (LTC) homes is now less than two years post-admission, making LTC a palliative care (PC) setting. As little is known about the readiness of LTC staff in Canada to embrace a PC mandate, the main objective of this study was to assess qualities relevant to PC... Overall, the results of this study suggest that the emotional wellbeing of the Canadian LTC workforce is unlikely to impede effective PC. However, PC self-efficacy and person-centred care can be further cultivated in this context. **Abstract (w. list of references):** <http://bit.ly/2VVbwh5>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 22 May 2018 – "**“Death by donation”: Why some doctors say organs should be removed from some patients before they die.**" Three years after assisted death became legal in Canada, the medical community is debating a provocative question: should organs be removed from consenting euthanasia patients while they're still alive? Some say changing the rules would allow people choosing an assisted death to donate as many organs as possible – in the most optimal condition possible – because blood and oxygen would continue to flow through vital organs until the moment of retrieval. Under this scenario, people granted an assisted death would, with their full knowledge and consent, be transported to an operating room, put to sleep under general anaesthesia and their organs removed, including the heart and lungs. Death would follow removal of the beating heart. Under so-called "euthanasia by organ donation," the act of organ donation itself – not a lethal injection or a doctor-prescribed, life-ending dose of barbiturates – would be the mode of death. Organ donation after euthanasia is already occurring, legally, in Canada. About 30 people who have died by "medical assistance in dying," or MAiD, since the law decriminalizing the act was passed in 2016 have consented to donate kidneys or other organs. <http://bit.ly/2Xgeqi9>

Noted in Media Watch (#548, p.2):

- CBC ('The Sunday Edition') | Online – 27 January 2018 – '**The benefits and perils of organ donation after assisted death.**' One area of ongoing ethical concern is the question of whether assisted death patients should be allowed to donate their organs. No federal law currently prohibits them from doing so, but the process is complicated and varies from province to province. Some bioethicists worry that allowing organ donation after assisted death may give people an additional incentive to end their lives, and that vulnerable patients could be pressured into giving up their organs for the good of society. Others believe that denying people the chance to help patients on the transplant list, and to find meaning at the end of their lives, is paternalistic and counterproductive. <http://bit.ly/2QvaQhw>

U.S.A.

State governments working to jump start palliative care

HOSPICE NEWS | Online – 30 May 2019 – Efforts by individual states to expand palliative care (PC) awareness and utilization foreshadow a national trend, with multiple states passing laws or mulling legislation during 2018 and 2019. This comes a time when hospices are increasingly diversifying their services to include PC. This year, Ohio passed a law requiring hospitals, ambulatory surgery centers, nursing homes, and other healthcare organizations in the state to develop systems to identify patients or residents who are in need of PC and inform them about the benefits and availability of those services. Ken-

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tucky in March approved legislation creating a Palliative Care Interdisciplinary Advisory Council and a professional information and education program to help foster PC awareness. New Jersey is currently considering similar legislation. As of December 2018, 27 states have laws on their books designed to promote PC, according to the National Academy of State Health Policy. Though details of the legislation vary among the states, they each serve the goal of bringing PC to more patients with serious, chronic, or life-limiting conditions. Lack of awareness is a major barrier to PC expansion. A recent study found that as many as 71% of people in the U.S. have little to no understanding of what PC is, including many clinicians in a position to refer patients to PC or hospice.¹ <http://bit.ly/2HMd09v>

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

Related

- **STATELINE** | Online – 29 May 2019 – '**Palliative care beyond hospice is spreading to more states.**' An estimated 40 million adults in the U.S. are living with or have had a serious illness in the last three years.¹ Many of them ... would benefit from palliative care (PC)... Now more states are taking steps to extend such coverage to millions more people. They are extending PC benefits to adult Medicaid beneficiaries who are not necessarily close to death, mandating providers tell patients that PC is available when it might be of some benefit, and requiring PC training for doctors. Maryland became the first state to require all hospitals with more than 50 beds to provide PC services. <http://bit.ly/2EIG3ZE>
 1. 'Health Care in America: The Experience of People with Serious Illness,' Commonwealth Fund, October 2018. **Download/view at:** <http://bit.ly/2wuNQpA>
- **NEW JERSEY** | *NJ Spotlight* (Newark) – 28 May 2019 – '**New Jersey takes next step toward palliative care education, outreach.**' New Jersey would establish an advisory council on palliative care (PC) and require hospitals, nursing homes, and other facilities to educate patients or their family members on their care options, under legislation now advancing in Trenton. The legislation ... calls for the state Department of Health to establish an outreach program and provider requirements and enables state leaders to appoint an 11-member advisory council to create the public materials and implement the program. <http://bit.ly/2l2aPOd>

Where Americans die now

OREGON | *The Oregonian* (Portland) – 27 May 2019 – Although more than 700,000 people die in hospitals each year in the U.S., the trend is toward fewer in-hospital deaths. According to the Centers for Disease Control & Prevention, the number of people dying in the hospital [2000-2010] dropped from 776,000 to 715,000 (an 8% drop),¹ even as hospital admissions increased from 31.7 million to 35.1 million (an 11% increase). Some of the most dramatic reductions in hospital deaths were among people with kidney disease and cancer. A July 2016 study ... found that deaths in the emergency room have dropped as well.² In fact, the study found that the number of deaths occurring in U.S. emergency rooms dropped by almost half between 1997 and 2011.² The actual rates reflect how rare emergency room deaths are: from 1.48 to 0.77 per 1,000 adults. It's unclear how much lower these numbers can go. Almost two-thirds of the deaths occurred among people who arrived in the ER unconscious, in cardiac arrest, or dead on arrival. <http://bit.ly/2YVtkdV>

Specialist Publications

'For service innovation in end-of-life care, branding and messaging matter' (p.6), in *Academy of Marketing Sciences Review*.

'Lessons learned from Hurricane Maria in Puerto Rico: Practical measures to mitigate the impact of a catastrophic natural disaster on radiation oncology patients' (p.11), in *Practical Radiation Oncology*.

Cont.

1. 'Trends in Inpatient Hospital Deaths: National Hospital Discharge Survey, 2000-2010,' Centers for Disease Control & Prevention, March 2013. **Download/view at:** <http://bit.ly/2HXnMsk>
2. 'Emergency department death rates dropped by nearly fifty percent, 1997-2011,' *Health Affairs*, 2016; 35(7):1303-1308, noted in 11 July 2016 issue of Media Watch, #470, p.4. **Full text (via PubMed):** <http://bit.ly/2WoJEq5>

“We carry a light”: Inmates at Shawnee Correctional Center care for the prison’s dying

ILLINOIS | *The Southern Illinoian* (Carbondale) – 26 May 2019 – Karen Smoot ... has worked for the Illinois Department of Corrections since 2016, and said hospice or end-of-life care (EoLC) is different for prisoners. They are not in their homes, in their own beds, and oftentimes are not surrounded by loved ones. But still, Smoot sees it as her job to comfort them. “We’re tasked with taking care of him and providing for him the appropriate and humane EoLC,” she said. Another thing that separates hospice care at Shawnee is the team of caretakers Smoot has assembled. The seven men that stood next to Ernest Cornes and have cared for his most intimate needs in the weeks he’s been in the infirmary were not nurses. They are inmates. Smoot said a 2017 directive came from the state that prisons in the Illinois Department of Corrections needed to implement some form of EoLC, and

she decided to go a bit further. She created the Shawnee Hospice/Adult Comfort Care Program, which trains select inmates in the type of therapeutic, non-medical care given to people who are nearing death. Smoot said that many who come to prison and through her program are not used to thinking beyond themselves – for some, that was a means of survival before they were incarcerated. The hospice program is a way, she said, for them to learn how to think about others. <http://bit.ly/2VSGLt0>

[Specialist Publications](#)

‘A systematic integrative review of programmes addressing the social care needs of older prisoners’ (p.7), in *Health & Justice*.

A final comfort for dying children: “Palliative transport” to send them home

THE WASHINGTON POST | Online – 26 May 2019 – Anthony’s journey was made possible through swift and unconventional efforts by the hospital staff, including a critical care transport team accustomed to rushing kids to the hospital to save their lives, not taking them home to die. The experience galvanized Harriett Nelson, a nurse on that team who helped manage the trip. It inspired her to conduct pioneering research on and advocate for “pediatric palliative transport” – a rare but growing practice that aims to give families choice, control and comfort at the end of life.¹ Palliative transport lets families move critically ill children from the hospital intensive care unit to their home or hospice, with the expectation they will die within minutes to days after removing life support. It means “having parents go

through the hardest thing they’ll ever know – in the way they want to do it,” Nelson said. Boston Children’s has sent 19 children to home or hospice through palliative transport since 2007, she said. These final journeys – also offered by the Mayo Clinic, Children’s Hospital of Philadelphia, and Kentucky Children’s Hospital – can involve elaborate planning, delicate transfers, and even long helicopter rides. <https://wapo.st/2W31vDC>

[Specialist Publications](#)

‘Stopping the momentum of clinical cascades in the pediatric intensive care unit: Intentional responses to the limits of medicine’ (p.9), in *Journal of Palliative Care*.

1. ‘Parents’ experiences of pediatric palliative transports: A qualitative case series,’ *Journal of Pain & Symptom Management*, 2015;50(3):375-380. **Full text:** <http://bit.ly/30MO0Xa>



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Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MAINE | *The Times Record* (South Portland) – 29 May 2019 – ‘**Maine House passes “death with dignity” bill by 4 votes.**’ The Maine House narrowly approved a bill that would allow terminally ill patients to end their own lives with a lethal dose of medication prescribed by a doctor. The so-called “death with dignity” bill cleared the House by just four votes, 72-68, with 11 lawmakers either absent or excused. A similar bill was rejected by the House in 2017, when 85 of the 151 lawmakers opposed the measure. The bill cuts across party lines, with Democrats and Republicans on both sides of the measure. If passed, Maine would become only the eighth state with a similar law on the books, following Oregon, which passed its law in 1997. <http://bit.ly/2W0IBbF>

International

Nurses struggling to look after dying patients due of staff shortages, survey finds

U.K. (England) | *The Independent* (London) – 28 May 2019 – Nurses are struggling to look after dying patients because of staff shortages, according to a survey. Two-thirds of nurses (65%) said staffing levels are the main “barrier” to providing good care in the final stages of patients’ lives, according to an annual poll by magazine *Nursing Standard* and charity Marie Curie. Last year, 38% reported the same reason. Meanwhile, more than half (57%) of nurses reported time constraints as an issue, compared to 25% last year. The survey, of more than 5,300 nurses and care staff, also found a third (33%) do not feel sufficiently supported at work to manage feelings of grief and emotional stress. Amanda Cheesley, from the Royal College of Nursing, said: “Staff shortages are placing nurses under intolerable strain right across the National Health Service (NHS), and it is not surprising that nurses caring for people at the end of life feel unable to provide the level of care that

these patients and their families expect and should have. “With a current shortfall of 40,000 registered nurse vacancies in England alone, it’s time for the government to change the law so that ministers and local NHS providers are explicitly accountable for making sure the NHS is safely staffed.” <https://ind.pn/2EGAMSp>

Specialist Publications

‘**Advance directives in the relationship between relatives and caregivers: The Swiss case**’ (p.10), in *Médecine Palliative*.

‘**Attitudes toward assisted suicide requests in the context of severe and persistent mental illness: A survey of psychiatrists in Switzerland**’ (p.13), in *Palliative & Supportive Care*.

N.B. Access to results of the survey requires a subscription to *Nursing Standard*: <http://bit.ly/2MiZdeE>



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>

Specialist Publications

For service innovation in end-of-life care, branding and messaging matter

ACADEMY OF MARKETING SCIENCES REVIEW | Online – 24 May 2019 – Many patients over 65 with advanced chronic illness undergo medical treatment that fails to align with their preferences as the end of life approaches. In particular, unwanted hospitalizations increase in number and duration, a pattern of overtreatment that not only violates patient choice but also constitutes preventable medical waste. Existing services that align care with patient preference are underused, in part because both physicians and patients associate them with dying and denial of treatment. An innovative program developed at Sutter Health, a large integrated system in Northern California, illustrates how to remedy this situation. Nurse-led teams bring care to the residences of more than 2,000 patients with advanced illness each day, increasing the quality of their care, reducing hospitalizations and lowering costs. Program branding and messaging has led to widespread acceptance, and

the initiative has become a foundational component of a new Medicare payment model. Skillful branding and messaging of service innovation initiatives can help to overcome the emotional and attitudinal barriers restricting the use of current service lines, changing the focus of care for seriously-ill people from the hospital to their homes. **Abstract (w. list of references):** <http://bit.ly/2wm7uUF>

Publishing Matters

'Rethinking impact factors: Better ways to judge a journal' (p.13), in *Nature*.

'Methodological management of end-of-life decision data in intensive care studies: A systematic review of 178 randomized control trials published in seven major journals' (p.13), in *Plos One*.

Evaluation of person-centeredness in nursing homes after a palliative care intervention: Pre- and post-test experimental design

BMC PALLIATIVE CARE | Online – 31 May 2019 – This study evaluated the staff's perception of providing person-centred palliative care (PC) for older persons in nursing homes after they participated in an educational PC intervention. The results indicated that the care and service provided at the nursing homes before the intervention had a person-centred approach, and the only perceived improvement area in person-centred care is the managers' and organization's support of the staff's everyday work in order to maintain person-centred care. The lessons learned from the study are to educate all staff at the participated nursing homes, more frequent training and use of a longer period than half a year and specifically educate some staff at each nursing home to educate newly employed staff on the person-centred PC approach. Not only staff needs education, but also front leaders, since the study found lack of leadership and embedded organisational support for person-centred care. Further research could focus on investigating front leaders' support to staff and removing obstacles for providing person-centred care. **Full text:** <http://bit.ly/2QzSAmW>

Impact of informational and relational continuity for people with palliative care needs: A mixed methods rapid review

BMJ OPEN | Online – 29 May 2019 – Continuity of care is difficult to deliver, and can be hard to measure, but is vitally important to patients. Relational continuity provides the context on which to build individualised care plans for patients, that in turn, requires informational and managerial continuity between services to be effective. Improving continuity in palliative care (PC) may not remove every negative experience for PC patients and their families. However, the contrasts in reports of patients who had, and had not, perceived continuity in their care in this review demonstrate the beneficial effects that continuity can have in terms of feeling safe, known and supported. While continuity may not be the panacea for all the challenges in providing high quality PC, the authors believe that good continuity, in a range of forms, can

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go a long way to improving a difficult time in a family or a person's life. This rapid review highlights the impact that continuity of care can have on the experiences of patients receiving PC. The evidence for the impact of continuity on place of death and hospital admissions is limited. Methods for enhancing, and recording continuity should be considered in the design and development of future healthcare interventions to support people receiving PC. **Full text:** <http://bit.ly/2W6JoYE>

When and how to use data from randomised trials to develop or validate prognostic models

BMJ OPEN | Online – 29 May 2019 – The development and validation of prognostic prediction models requires substantial volumes of high quality information on relevant predictors and patient health outcomes. Primary data collection dedicated to prognostic model (development or validation) research could come with substantial time and costs and can be seen as a waste of resources if suitable data are already available. Randomised clinical trials are a source of high quality clinical data with a largely untapped potential for use in further research. This article addresses when and how data from a randomised clinical trial can be used additionally for prognostic model research, and provides guidance for researchers with access to trial data to evaluate the suitability of their data for the development and validation of prognostic prediction models. **Abstract:** <http://bit.ly/217EkhG>

Palliative care: A systematic review of evidence-based interventions

CRITICAL CARE NURSING QUARTERLY, 2019;42(3):315-328. The authors conducted an integrative review to determine evidence-based and most efficient strategies for improving the palliative care (PC) of patients at the end-of-life stage. Thirteen articles that met the overall inclusion criteria were evaluated. Key aspects included communication and coordination among the team members – patient-centered approach. The major theme was the application of a holistic approach to PC consisting of providing comfort to the dying patient. It was identified that relationships, which were identified as spiritual needs, are also crucial to the improvement of PC. Improving nursing education in this area, undertaking appropriate curriculum development, and providing coordination among training programs will help knowledgeable healthcare providers deliver compassionate, affordable, sustainable, and high-quality care to a growing population of aging patients facing the end of their lives. **Abstract:** <http://bit.ly/2MeVgYP>

A systematic integrative review of programmes addressing the social care needs of older prisoners

HEALTH & JUSTICE | Online – 27 May 2019 – This review details programmes which support older prisoners' social care needs, including hospice and structured programmes, personal care-focused services, and regime and accommodation adaptations. Whilst the papers presented largely positive results regarding prisoner peer supporters and the wider prison, there were mixed results for staff. Additionally, whilst there were positive claims made about the impact on the prisoners attending the programmes, only two papers actually sampled those prisoners. This together with the generally low quality of the papers, and lack of any experimental effectiveness studies, to some extent limits their utility for policy and practice. There is a clear need for more robust effectiveness and cost-effectiveness studies to better support the development of social care for older prisoners at individual, policy and practice levels. **Full text:** <http://bit.ly/2YOZo2U>

N.B. EoLC in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., (updated 20 May 2019) noted in past issues of the weekly report can be downloaded/viewed on the Palliative Care Network website at: <http://bit.ly/2RdegnL>



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

Common risk stratification of hospital and ambulatory patients

JOURNAL FOR HEALTHCARE QUALITY | Online – 22 May 2019 – The care of patients with multiple chronic conditions and those near the end-of-life is often compromised by miscommunications among the healthcare teams. These might be improved by using common risk strata for both hospital and ambulatory settings. The authors developed, validated, and implemented an all-payer ambulatory risk stratification based on the patients' predicted probability of dying within 30 days, for a large multispecialty practice. Strata had comparable 30-day mortality rates to hospital strata already in use. The high-risk ambulatory strata contained less than 20% of the ambulatory population yet captured 85% of those with 3 or more comorbidities, more than 80% of those who would die 30 or 180 days from the date of scoring, and two-thirds of those with a non-surgical hospitalization within the next 30 days. The authors provide examples how the practice and partner hospital have begun to use this common framework for their clinical care model. **Abstract:** <http://bit.ly/2WsbAJB>

Value of the nursing assistant in palliative care

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(3):E13-E14. It is the position of the Hospice & Palliative Nurses Association that: 1) Nursing and healthcare organizations recognize that care provided by nursing assistants is critical to achieving established goals of care for patients with serious illnesses and their families; 2) Registered nurses recognize that nursing assistants are a vital and important member of the palliative care (PC) team. (Nursing assistants deliver care that assists the registered nurse in accomplishing the patient's and family's goals and plan of care); 3) Healthcare institutions and organizations must ensure that nursing assistants in all settings receive adequate educational preparation and continuing education to care for patients with serious illnesses and their families; 4) Nurses and administrators in all PC settings must advocate for and ensure the inclusion and recognition of nursing assistants as key members of the interdisciplinary team who are valued and deserving of competitive wages; 5) Specialty certification of the hospice and palliative nursing assistant is a means for recognition and advancement of this essential component of the palliative interdisciplinary team; and, 6) Individuals developing policies, procedures, and protocols must ensure the role of the hospice and palliative nursing assistant is consistent with individual state nurse practice acts, the Statement on the Scope and Standards for Hospice and Palliative Nursing Assistant Practice, and Hospice & Palliative Nursing Assistant Competencies.^{1,2} **Full text:** <http://bit.ly/2wv1vNi>



1. 'Statement on the Scope and Standards for Hospice and Palliative Nursing Assistant Practice,' Hospice & Palliative Nurses Association, 2018. **Download/view at:** <http://bit.ly/2W1YgHo>
2. 'Hospice & Palliative Nursing Assistant Competencies,' Hospice & Palliative Nurses Association, 2009. **Download/view at:** <http://bit.ly/2wv39ys>

Hospice in the U.S.

Implementation of a clinical pharmacist service in the hospice setting: Financial and clinical impacts

JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY | Online – 28 May 2019 – Hospice is a unique environment among all clinical fields of practice. Although every other specialty aims to work toward a curative goal or prevention of mortality, hospice completely redirects focus solely on pain and symptom management and sustaining the highest quality of life possible. Addition of a clinical pharmacist to the interdisciplinary group (IDG) is not common, but Haven: Advanced Illness Care [Gainesville, Florida] added a clinical pharmacist to the team in 2017. Substantial financial impacts were made in the first year, and clinical impacts were well regarded by physicians and nurses. A cost savings of \$427,705 was observed, and the clinical pharmacist provided a great deal of expertise to the IDG. Adding a clinical pharmacist to the IDG of other hospice organizations may prove to be a worthy investment. **Abstract:** <http://bit.ly/2XcSlkp>

Masculinity and military culture in Veterans Affairs hospice and palliative care: A narrative review with clinical recommendations

JOURNAL OF PALLIATIVE CARE | Online – 30 May 2019 – The authors conducted a narrative literature review, supplemented with clinical annotations, to identify the impact of masculinity and military culture on the following topics salient to end-of-life (EoL) care with older male veterans: pain management, mental health, coping, communication, autonomy and respect, and family roles. Findings suggest that traits associated with masculinity and military culture have an influence on the EoL process and hospice and palliative care (HPC) for older male veterans. Specifically, results suggest that older male veterans may deny or minimize physical pain, decline mental health treatment, utilize maladaptive coping strategies, avoid emotional conversations, struggle to manage perceived shifts in autonomy, and experience challenges negotiating changing family roles. The authors provide clinical recommendations for providers across various disciplines to address the aforementioned concerns with older male veterans in HPC. Overall, information presented in this article may be an important contribution to the literature for building cultural competencies with older male veterans and has the potential to improve the delivery of HPC for veterans and their families. **Abstract:** <http://bit.ly/2HQyTEZ>

Stopping the momentum of clinical cascades in the pediatric intensive care unit: Intentional responses to the limits of medicine

JOURNAL OF PALLIATIVE CARE | Online – 29 May 2019 – The majority of pediatric deaths occur in intensive care units and, among children who survive their pediatric intensive care unit (PICU) stay, many are left with significant morbidities, profound disability, and/or technology dependence. Additionally, more than 50% of children admitted to the PICU have baseline chronic medical conditions, and these patients are at increased risk of mortality, prolonged ICU length of stay, and aggressive interventions that clinicians may assumed to be desired by families because they utilized them in the past. Oftentimes, these outcomes are the consequence of a cascade of interventions that, over time, have diminishing potential to improve patient survival. Ensuring evidence-based and goal-focused decision-making in the context of critical illness and end-of-life care is one of the most challenging responsibilities of PICU providers. The ability to prognosticate recovery or death is imperfect, and this uncertainty has a significant impact on provider decision-making as well as communication related to the limitation of life-sustaining treatment. Often out greatest challenge comes when we recognize, or fail to recognize, that the limitations of medicine have been reached. **First page view:** <http://bit.ly/2wuDA0E>

Palliative care and paediatric cardiology: Current evidence and future directions

THE LANCET: CHILD & ADOLESCENT HEALTH | Online – 22 May 2019 – Although outcomes for children with heart disease have improved substantially over the past several decades, heart disease remains one of the leading causes of paediatric mortality. For children who progress to advanced heart disease, disease morbidity is high, with many children requiring multiple surgical interventions and long-term intensive care hospitalisations. Care for children with advanced heart disease requires a multidisciplinary approach, and opportunities for earlier integration of palliative care (PC) are being explored. This viewpoint summarises the relevant literature over the past decade. The authors also identify gaps in parent and provider understanding of prognosis and communication, propose indications for PC consultation in paediatric advanced heart disease, and summarise attitudes and perceived barriers to PC consultation. Areas for additional research that are identify include paediatric cardiologist education, parental distress, socioeconomic disparities, and patient-reported outcomes. Interdisciplinary clinical and research efforts are required to further advance the field and improve integration of PC in the care of children with heart disease. **Abstract (w. list of references):** <http://bit.ly/2JMlIXz>

The hospitalization of a parent in palliative care: Adult children's perceptions of changes in the relationship

MÉDECINE PALLIATIVE | Online – 29 May 2019 – In Quebec, as in other parts of the world, support for families affected by palliative care (PC) is considered a priority. However, few studies have examined how the relationship between family members, which plays an essential role in the well-being of patients and their loved ones, is affected by the hospitalization of a member of the family in PC. Results [of this study] reveal changes in verbal and non-verbal communication, including the emergence of gestures of affection and symbolic connections. The adoption of context-specific relational roles, issues related to perceptions of involvement, and the intensity of the affective experience are also noted. In addition, certain beliefs about death and ways to attain closure may influence the relational experience of patients' loved ones. Hospital staff also appear able to indirectly impact the family relationship, according to [study] participants. This study attempts to describe channels through which family relationships evolve in the context of inpatient PC. It also reveals the role that meaning creation plays in adult children's experience. Finally, it informs PC providers about important aspects to consider when providing support to adult children. **Abstract:** <http://bit.ly/2lbrY6>

N.B. French language article.

Advance directives in the relationship between relatives and caregivers: The Swiss case

MÉDECINE PALLIATIVE | Online – 27 May 2019 – In Swiss legislation, advance directives (ADs) are designed as an instrument enabling the future patient to state his will with respect to potential medical treatments in situations where he is no longer capable of discernment. How and with what effects are these ADs perceived and used in practice by the actors in charge of the patient in end-of-life (EoL) situations in nursing home and at home? Collective interviews were conducted in three linguistic regions of Switzerland with doctors (12), nurses (11), and relatives (six and three interviews). A content analysis shows that ADs are often used as a lever to open a dialogue on the EoL from a patient's self-determination perspective. In home situations, however their implementation is difficult because relatives are responsible for their application. In nursing home, to the contrary, the presence of multiple caregivers blurs responsibility and thus facilitates decision-making. In both contexts, the burden of patient self-determination, which the legislator intended to be lever against medical power, weighs mainly on relatives and caregivers. **Abstract:** <http://bit.ly/2X5oj1T>

N.B. French language article.

Knowledge and attitudes regarding hospice care among outpatients and family members in two hospitals in China

MEDICINE, 2019;98(6): e15230. Access to hospice care is widely provided in Western countries, but the supply of such service is still in its initiative stage in China. As relatives are often involved in end-of-life decision making in China, a better understanding of their cognitions toward hospice care would help policy makers and physicians to overcome the barriers of providing such service. A total of 550 respondents completed a survey. Only 107 (19.5%) reported that they had known or heard of hospice care, with a mean knowledge score of 2.8. Of the respondents, 69.5% answered "strongly agree" or "agree" regarding the importance of providing hospice care in China. The awareness rate of hospice care is low, which may lead to poor attitude and low enrollment rate. Considering the

increasing evidence to support the improved outcomes of patients and family members associated with hospice care, the public education on its scope of services, benefits, and limitations is needed in China. **Full text:** <http://bit.ly/2W633Yn>

Words do matter

The Google translation of "palliative care" into Chinese is "姑息治疗." Back translated, the meaning is essentially "do nothing care." The Google translation of "hospice" is "临终关怀," literally meaning "last minute care." Is it any wonder that Chinese patients whose goals are comfort oriented end up declining hospice and palliative care once they hear the translated words? **Source:** GeriPal: <http://bit.ly/30BHGlq>

The meaning of dignity when the patients' bodies are falling apart

NURSING OPEN | Online – 22 May 2019 – The patients' experiences of their bodily changes gave insight into the phenomenon of dignity. The sick bodies force the patients, or give them the possibility, to deal with their bodies in an honest way when they can no longer cover up or hide the bodily changes, not from themselves, nor from the surroundings. The patients live in an interaction between health and suffering and reconcile, or acknowledge, the possibilities that life gives. This yields insight into dignity as the good ambiguity. Secondly, the life-affirming will is discovered as a natural force in the wrecked body, a force that helps the patients achieve health and experience dignity.

The patients willingly push their bodies and defy both pain and fatigue to feel and show that they are still alive and that their bodies are still able to carry them. Lastly, love is discovered as a healing power in the new and health-inducing rooms that the patients explore in their sick bodies. A love that alleviates suffering and promotes dignity. **Full text:** <http://bit.ly/2wqlq2c>



Do not resuscitate tattoos: Adequate evidence of a patient's intent to die?

OREGON LAW REVIEW | Online – Accessed 31 May 2019 – As DNR tattoos gain popularity, medical providers are increasingly forced to determine their patients' most vital, life-determining intentions without clear guidance from their patients or from the law. When presented with a tattoo that signifies medical wishes, doctors and other medical staff must try to best determine whether the tattoo represents a patient's true desire to make an irreversible medical decision. Can a tattoo adequately indicate a patient's current intent to die? This article discusses the history of medical tattoos, the emergence of end-of-life intention tattoos (including DNR tattoos), and the impact of DNR tattoos on medical providers and hospital ethics committees. The author provides suggestions for the use of tattoos as a proxy for valid statutory DNR orders. **First page view:** <http://bit.ly/2JninHT>

N.B. Additional articles on DNR tattoos noted in 17 December 2018 issue of Media Watch, #594, p.8.

Palliative Medicine 2018 Paper of the Year Award

End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care

PALLIATIVE MEDICINE, 2018;36(1):36-45. Given the unique and complex needs of homeless people with advanced ill health, specialised, flexible services are key in promoting compassionate, coordinated care. This will require a joint response from health, housing and social services. At the minimum, this should include increased collaboration between services, the promotion of in-reach into hostels and greater training and support for all professional groups. A bespoke service, providing an appropriate level of care and support for homeless people who are dying, in an environment in which they can feel comfortable may also be required. **Full text:** <http://bit.ly/2wo67op>



N.B. The *Palliative Medicine* award was announced at the recent European Association for Palliative Care Congress in Berlin. The article was first published online 3 July 2017 and noted in 10 July issue of Media Watch, #520, p.5. Additional articles on end-of-life care for the homeless in the U.K. noted in 15 April 2019 issue of Media Watch, #610, p.6.

Lessons learned from Hurricane Maria in Puerto Rico: Practical measures to mitigate the impact of a catastrophic natural disaster on radiation oncology patients

PRACTICAL RADIATION ONCOLOGY | Online – 15 April 2019 – Although the wind, rain, and flooding of Hurricane Maria in Puerto Rico abated shortly after its landfall on 20 September 2017, the disruption of the electrical, communications, transportation, and medical infrastructure of the island was unprecedented-

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ed in scope and caused lasting harm for many months afterward. A compilation of recommendations from radiation oncologists who were in Puerto Rico during the disaster, and from a panel of American Society for Radiation Oncology cancer experts was created. This paper draws upon the experience of radiation oncologists attempting to care for patients in the aftermath of Hurricane Maria and proposes some initial steps, therapeutic approaches, and minimal guidelines to address the shortcomings and needs that proved most urgent in the first weeks of recovery. In essence, this is a list of what the authors wished they had done beforehand and what we needed most afterward. The authors include Puerto Rican radiation oncologists and disease-site experts, all of whom hope that this document can serve as a first step toward establishing more structured preparations for disaster, tailored to the circumstances of all our practices as we attempt to serve our patients. **Full text:** <http://bit.ly/2XaDEOz>

N.B. Selected articles on integrating palliative care and symptom relief into responses to humanitarian emergencies and crises noted in 27 May 2019 issue of Media Watch, #615, p.10.

“We have no crystal ball”

Advance care planning at nursing homes from the perspective of nurses and physicians

SCANDINAVIAN JOURNAL OF PRIMARY HEALTH CARE | Online – 24 May 2019 – The analysis of interviews [with 14 physicians and 11 nurses working at 9 nursing homes in Sweden] resulted in four manifest categories: 1) Exploration of preferences and views, e.g., exploring patient wishes regarding end-of-life (EoL) issues and restrictions in care at an early stage, and sensitivity to patient’s readiness to discuss EoL issues; 2) Integration of preferences and views, e.g., integration of patient’s preferences and staff’s and family member’s views; 3) Decision and documentation of the advance care plan (ACP), e.g., clear documentation in patient’s medical records that are up-to-date and available for staff caring for the patient; and, 4) Implementation and re-evaluation of the ACP, e.g., nurse following up after ACP-appointment to confirm the content of the documented ACP. The latent theme, establishing beneficence – defending oneself against tacit accusations of maleficence, emerged as a deeper meaning of all the four (manifest) parts of the ACP-process. This study stresses the importance of involving patients, family members, and the team in the work with advance care planning in nursing homes. In addition, clear medical record documentation and proficiency in EoL communication related to advance care planning for physicians as well as nurses may also be factors that significantly shape advance care planning in a nursing home context. **Full text:** <http://bit.ly/30Kb2y2>



Assisted (or facilitated) death

Representative sample of recent journal articles:

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 31 May 2019 – ‘**Educational needs of healthcare professionals and members of the general public in Alberta, Canada, 2 years after the implementation of medical assistance in dying.**’ An online 2017-2018 survey of Alberta health-care providers and members of the general public was conducted to assess and compare their knowledge of medical assistance in dying (MAiD). Educational needs were clearly evident as only 30.5% [of respondents] knew the correct approximate number of MAiD deaths to date, 33.0% correctly identified the point in life when MAiD can be done, 48.9% correctly identified the locations where MAiD can be performed, 49.3% correctly identified who can stop MAiD from being carried out, and 52.8% correctly identified how MAiD is performed to end life. These findings indicate new approaches to meet sudden assisted suicide educational needs are needed. **Abstract:** <http://bit.ly/2Xjt6wG>

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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.14.

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 27 May 2019 – ‘**Attitudes toward assisted suicide requests in the context of severe and persistent mental illness: A survey of psychiatrists in Switzerland.**’ Switzerland is among the few countries worldwide where a request for assisted suicide (AS) can be granted on the basis of a primary psychiatric diagnosis. Psychiatrists play an increasingly important role in this regard, especially when the request for AS arises in the context of suffering caused by severe and persistent mental illness (SPMI). Although a majority of psychiatrists [i.e., survey respondents] did not support AS for SPMI patients, about one-third would have supported the wishes of patients in the case vignettes. In light of the increasing number of psychiatric patients seeking AS and the continuing liberalization of AS practices, it is important to understand and take account of psychiatrists’ perspectives. **Abstract (w. list of references):** <http://bit.ly/30O8bUB>

[Publishing Matters](#)

Rethinking impact factors: Better ways to judge a journal

NATURE | Online – 28 May 2019 – Global efforts are afoot to create a constructive role for journal metrics in scholarly publishing and to displace the dominance of impact factors in the assessment of research. To this end, a group of bibliometric and evaluation specialists, scientists, publishers, scientific societies and research-analytics providers are working to hammer out a broader suite of journal indicators, and other ways to judge a journal’s qualities. It is a challenging task: interests vary and often conflict, and change requires a concerted effort across publishing, academia, funding agencies, policymakers and providers of bibliometric data. **Full text:** <https://go.nature.com/2YVqdTs>

Methodological management of end-of-life decision data in intensive care studies: A systematic review of 178 randomized control trials published in seven major journals

PLOS ONE | Online – 28 May 2019 – The findings of the authors’ review reflect a lack of precision in the end of life (EoL) description in reports of ICU clinical trials and the heterogeneity of their methodological management. This systematic review illustrates the need to elaborate on recommendations regarding inclusion/exclusion of patients with EoL decisions in randomized controlled trials and to publish rules on reporting and analyzing the data. At least a systematic and precise report of the rate and type of EoL, the delay between EoL and death, and the statistical approach used to consider EoL should be reported for ICU clinical trials. **Full text:** <http://bit.ly/2KcU45I>

[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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1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.

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3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Media Watch: Access on Online

International



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

[Scroll down to 'Media Watch: On Dementia']

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

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

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

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

Asia

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

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

Canada



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

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

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

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <http://bit.ly/2G2tf1W>

HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RgTvYr>

U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

United States

NEBRASKA | Center for Health Policy & Ethics, Creighton University: <http://bit.ly/2DAED3f>

[Scroll down to 'Barry Ashpole's Media Watch']

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