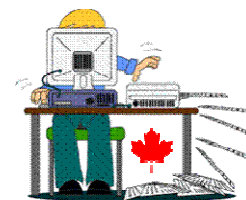


Media Watch...

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

Misunderstandings are pervasive throughout the United Nations system, national healthcare systems, the media, and the general public. Policymakers and providers who are somewhat familiar with palliative care stigmatize this relatively new public health approach as *only* appropriate for end of life, or *only* for cancer...

'Palliative care advocacy: Why does it matter?' (p.9), in *Journal of Palliative Medicine*.

Canada

Blueprint for Action 2020-2025

QUALITY END-OF-LIFE CARE COALITION OF CANADA | Online – 12 March 2020 – One of the key challenges over the next five years will be informing Canadians that hospice palliative care (HPC) is an essential service that should be provided to everyone. The Coalition has identified four priorities areas: 1) Increasing public awareness around HPC's benefits, issues and areas needing improvement, including support for caregivers and those experiencing grief and bereavement; 2) Ensuring healthcare providers, volunteers, communities, formal and informal caregivers and others have access to education and training to ensure they possess the required competencies to provide optimal care; 3) Contributing to systematic, standardized research and data collection on HPC with special interest including formal and informal caregivers, and grief and bereavement; and, 4) Advocating for universally accessible and culturally safe access to HPC for under-served populations and those who provide caregiving and experience grief and

bereavement. The Coalition will advocate for the creation of a Canadian Hospice Palliative Care Implementation Collaborative as part of the 'Framework on Palliative Care in Canada' that will enable a fully engaged strategy with a patient-centric approach to HPC.¹ **Download/view at:** <http://bit.ly/3aSzVMm>

Specialist Publications

'Pallium Canada's curriculum development model: A framework to support large-scale courseware development and deployment' (p.11), in *Journal of Palliative Medicine*.

'Value-based issues and policy change: Medical assistance in dying in four narratives' (p.14), in *Social & Policy Administration*.

1. 'Framework on Palliative Care in Canada,' Health Canada, 2018. [Noted in 10 December 2018 issue of Media Watch (#593, p.1)] **Download/view at:** <http://bit.ly/2AVEghF>

Fraser Health vs. the Delta Hospice Society: The usurpation of personal responsibility and...

BRITISH COLUMBIA | *The Delta Optimist* (Ladner) – 8 March 2020 – Last month, Fraser Health followed through on an ultimatum to the Delta Hospice Society: provide Medical Assistance in Dying or lose funding. The Delta Hospice Society refused to compromise their principles that palliative care (PC) “intends neither to hasten or postpone death.” This definition of PC is not specially crafted by the Delta Hospice Society; it is part of the World Health Organization’s definition of PC.¹ The story of the Delta Hospice Society is the story of private citizens who want to give back to their community by caring for their neighbours. Over the course of almost 30 years, hundreds of people have donated time and/or money to the hospice. In 2007, Fraser Health and the provincial government partnered with the hospice, recognizing the excellent work it was already doing and assisting the hospice to build and operate a new 10-bed facility. This illustrates Canadian society at its finest; people from all walks of life coming together to help care for their fellow citizens, with those actions supported by local governments. Fraser Health’s withdrawal of funding shatters this model of cooperation. Instead of enabling a compassionate citizenry to take initiative to care for their neighbours, Fraser Health is squashing this personal initiative. <http://bit.ly/3cGHG9D>

1. World Health Organization’s definition of PC: <http://bit.ly/2xgUTWq>

N.B. Press coverage regarding Delta Hospice Society noted in 2 March 2020 issue of Media Watch (#655, p.1). Download/view the Society’s press release issued 28 February 2020 in response to the provincial government’s decision to withdraw funding at: <http://bit.ly/2Vz7Xkk>

U.S.A.

Hospice advocates ask White House for COVID-19 disaster declaration, waivers for hospice

HOSPICE NEWS | Online – 11 March 2020 – Hospice industry groups are calling on the Trump Administration to allow the Centers for Medicare & Medicaid Services (CMS) to relax hospice regulations in response to the COVID-19 crisis. The National Hospice & Palliative Care Organization has asked the White House in a letter to declare the pandemic a national disaster, allowing hospices and other healthcare providers some flexibility in complying with Medicare Conditions of Participation.¹ In addition, the National Association for Home Care & Hospice addressed a letter to CMS Administrator Seema Verma likewise asking for additional flexibility for healthcare providers who care for patients in the home setting.² A disaster declaration would allow CMS to issue a waiver for healthcare organizations, including hospice that would relax some CMS rules regarding the timeframes for the initial and comprehensive assessments, updates to care plans, allow for contracting for core services, rules governing volunteer activities and other provisions. Potential CMS actions such as ex-

panding the use of telemedicine – and ensuring providers can be reimbursed for it – could go a long way. <http://bit.ly/2xq2xOi>

Specialist Publications

‘Lack of awareness and common misconceptions about palliative care among U.S. adults: Insights from a national survey’ (p.9), in *Journal of General Internal Medicine*.

‘Masculinity and military culture in Veterans Affairs hospice and palliative care: A narrative review with clinical recommendations’ (p.9), in *Journal of Palliative Care*.

‘Characteristics of hospices providing high-quality care’ (p.10), in *Journal of Palliative Medicine*.

‘Differences of quality in end-of-life care across settings: Results from the U.S. National Health & Aging Trends Study of Medicare Beneficiaries’ (p.10), in *Journal of Palliative Medicine*.

1. National Hospice & Palliative Care Organization letter to the White House: <http://bit.ly/3aN7Cia>

2. National Association for Home Care & Hospice letter to Centers for Medicare & Medicaid Services, March 2020: <http://bit.ly/2Q9ei25>

N.B. Center to Advance Palliative Care statement on COVID-19 (11 March 2020): <http://bit.ly/2TOQh2w>

Coalition releases 2019 Impact Report

NATIONAL COALITION FOR HOSPICE & PALLIATIVE CARE | Online – 25 February 2020 – The Coalition has released its inaugural 2019 Impact Report that provides an overview of accomplishments achieved in five strategic priority areas: 1) Advocacy; 2) Payment; 3) Quality; 4) Research; and, 5) Workforce. The mission of the Coalition is to present a united voice to the public and policy makers on behalf of providers, professionals and other organizations that will improve the care of people living with serious or life-threatening illnesses. **Download/view report at:** <http://bit.ly/2IHmjHL>

Related:

- CNBC NEWS | Online – 13 March 2020 – **‘71% of Americans don’t know what palliative care is even though it can save patients thousands...’** While more doctors and specialized teams may sound expensive, those who utilize palliative care (PC) actually can save money. On average, hospital costs are about \$3,000 lower if patients start on PC within three days of being admitted, according to a study published in *JAMA Internal Medicine*.¹ The study found that PC led to shorter hospital stays, which can result in significant savings when you consider each day can cost hundreds of dollars. And yet 71% of Americans say they know nothing about PC, according to an analysis of the 2018 National Cancer Institute’s Health Information National Trends Survey.² <https://cnb.cx/2WfaiRB>
- 1. ‘Economics of palliative care for hospitalized adults with serious illness: A meta-analysis,’ *JAMA Internal Medicine*, 2018;178(6):820-829. [Noted in 11 June 2028 issue of Media Watch (#567, p.9)] **Full text:** <http://bit.ly/2TgDcO6>
- 2. ‘Knowledge of palliative care among American adults: 2018 Health Information National Trends Survey,’ *Journal of Pain & Symptom Management*, published online 25 March 2019. [Noted in 1 April 2019 issue of Media Watch (#608, p.12)] **Abstract (inc. link to references):** <http://bit.ly/2JCTteG>

International

Abandoned children in need of end-of-life care find new home in rural KwaZulu-Natal

SOUTH AFRICA | *City News* (Johannesburg) – 10 March 2020 – Abandoned children from government hospitals are finding a new home in a far-flung corner of rural KwaZulu-Natal (KZN), as one foster family is giving hope to children in need of end-of-life care (EoLC). Tarryn Bell and her husband, Dr. Christoff Bell, are the founders of Butterfly Home, a foster home tucked away in the lush green landscape of Ingwavuma in rural northern KZN. But Butterfly Home is no ordinary foster home, and only takes children in need of EoLC. Butterfly Home, part of Izandla zeAfrika, a registered non-profit organization, turns two in May of this year, and Bell plans to register the facility as a full-time hospice for children. According to the Department of Social Development, when a palliative child is abandoned in hospital it is the responsibility of the Department of Health to keep the child in care until a social worker can evaluate the child’s circumstances. In 2016, the Department of Health reported partnerships with non-government organizations ...

that controlled 21 facilities that could provide palliative care for adults and children. According to Palliative Treatment for Children South Africa, there are four registered hospice facilities specifically for children in KZN. <http://bit.ly/3393YMY>

Specialist Publications

‘The dying parent and dependent children: A nationwide survey of hospice and community palliative care support services’ (p.7), in *BMJ Supportive & Palliative Care*.

‘Portuguese Patient Dignity Question: A cross-sectional study of palliative patients cared for in primary care’ (p.12), in *Palliative & Supportive Care*.

‘Improving palliative and end-of-life care for rural and remote Australians’ (p.13), in *Public Health Research & Practice*.

Chancellor urged to use budget to save U.K.'s hospices from financial collapse

U.K. (England) | *The Daily Mirror* (London) – 8 March 2020 – Charities are calling for an urgent funding increase to help the country's 200 hospices which provide care for more 225,000 people a year. The homes for people with terminal and life-limiting conditions rely on voluntary donations for two-thirds of their income. But many are struggling to raise funds at a time when there is an increased demand for their services. *The Daily Mirror* is campaigning for the Government to double its funding to hospices, end the postcode lottery of hospice care, recruit more palliative care (PC) doctors and community nurses and to guarantee that all terminally ill children receive end-of-life care. In a letter to Chancellor Rishi Sunak ahead of next week's budget, the charity Sue Ryder says the lack of secure funding is putting care for vulnerable people "at unnecessary risk" ... [and] ... "By providing specialist PC, hospices including hospice at home help the wider system by freeing up hospital beds that would otherwise be occupied

by people at the end of life." National Health Service England has pledged to raise funding for children's hospices to £25 million in 2023-2024, and the Conservative Party pledged to "support our precious hospices" in its election manifesto. <http://bit.ly/3cHCh21>

Extract from letter to Chancellor Rishi Sunak

Despite the expert, compassionate PC provided in our hospices and their local communities to people with a terminal illness and at the end of life, hospices receive on average only enough funding to cover one third of their costs. Indeed, some of our own hospices receive as little as 28% of their funding from statutory sources and for the vast majority of our hospices statutory funding has stayed the same or decreased over the last 5 years, while costs have increased significantly. The rest of our income is fundraised and is therefore reliant on goodwill. This places care for people at their most vulnerable at unnecessary risk.

Noted in 3 February 2020 (#651, p.4):

- U.K. | *The Daily Mirror* (London) – 30 January 2020 – **“We must act now to save our hospices – or children will go without care.”** As part of its long-term plan, National Health Service England has pledged to raise funding for children's hospices to £25 million in 2023-2024, and the Conservative Party pledged to "support our precious hospices" in its election manifesto. A report from Together For Short Lives, a charity which represents hospice users, warns of a "children's palliative care (PC) workforce crisis."¹ It says services are at "breaking point" because of a growing shortage of PC doctors and nurses. The report shows there are just fifteen children's PC consultants in the U.K. when there should be forty to sixty. <http://bit.ly/2GCXwU9>
 - 'Open letter delivered to Secretary of State,' Together for Short Lives, January 2020. **Download/view** at: <http://bit.ly/2OgFIT3>

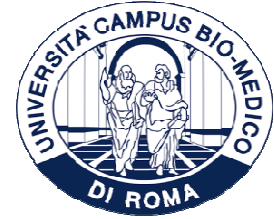
Noted in Media Watch 21 October 2019 (#636, p.5):

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

Specialist Publications

Inequity in palliative care service full utilisation among patients with advanced cancer: A retrospective cohort study

ACTA ONCOLOGIA | Online – 9 March 2020 – Advanced cancer patients often die in hospital after receiving needless, aggressive treatment. Although palliative care (PC) improves symptom management, barriers to accessing PC services affect its utilisation, and such disparities challenge the equitable provision of PC. 13,656 patients residing in the Lazio region of Italy, who died of an advanced cancer-related cause – either in hospital or in a specialised PC facility – during the period of 2012-2016 were included in the study. Potential predictors of specialised PC utilisation were explored by grouping the following factors: predisposing factors (i.e., individuals' characteristics), enabling factors (i.e., systemic/structural factors) and need factors (i.e., type/severity of illness). This study found that socio-demographic (age, ethnicity), clinical (type of tumour, survival time) and organisational (area of residence, distance from service) factors affect the utilisation of specialised PC services. The fact that service utilisation is not only a function of patients' needs but also of other aspects demonstrates the presence of inequity in access to among advanced cancer patients. **Abstract:** <http://bit.ly/3cP0Pqf>



Related:

- *BMC PALLIATIVE CARE* | Online – 12 March 2020 – ‘**First referral to an integrated onco-palliative care program: A retrospective analysis of its timing.**’ In the early phase of long lasting incurable disease, patients with no uncontrolled symptoms and no psychosocial needs have no *a priori* reason to benefit from palliative care (PC). In the model the authors describe, the shared-discussion process that took place in onco-palliative meetings worked as a screening tool to identify patients who will benefit from a PC program. In the screening process both time-based and needs-based criteria are taken into account. In a perspective of practice analyses in multicentre setting, the index of precocity could be an interesting tool to describe actual integration of PC... **Full text:** <http://bit.ly/2QdiRbR>

Effect of an interactive website to engage patients in advance care planning in outpatient settings

ANNALS OF FAMILY MEDICINE, 2020;18(2):110-117. In this multi-site implementation study among older adults from primary care and outpatient cancer clinics, patients' engagement in advance care planning (ACP) increased after self-directed use of the online PREPARE program at home. ACP behavior change process scores increased by a mean of 0.6 on a 5-point scale. A change of this magnitude demonstrates that patients are moving along the behavior change pathway from pre-contemplation, to contemplation, to preparation, to action. Although a score change of approximately 1.0 has been associated with prior advance directive completion, the observed change in scores in this study demonstrates that patients are engaging more in a range of ACP behaviors, such as contemplation and discussion of wishes. **Full text:** <http://bit.ly/2VZgHAa>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 13 March 2020 – ‘**Advance care planning in chronically ill persons diagnosed with heart failure or chronic obstructive pulmonary disease: An integrative review.**’ Chronic diseases such as heart failure and chronic obstructive pulmonary disease have a high symptom burden punctuated by exacerbations, making it difficult to know when introduction of advance care planning (ACP) discussions would be most beneficial. Future research should focus on a deeper evaluation of when to introduce ACP conversations in this population and which ACP interventions are effective to facilitate these discussions. **Abstract (w. list of references):** <http://bit.ly/2QbZuQh>

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 13 March 2020 – ‘**Advance directive as Ulysses contract: The application of stopping of eating and drinking by advance directive.**’ Particular focus has been placed on the request to have assisted oral feedings withheld, the so-called Stopping of Eating & Drinking by Advance Directive (SED by AD), the purpose of which is to hasten death. This article reviews the available literature regarding the practice of SED by AD and explores the clinical and ethical aspects as they present at the bedside. The review aims to show that practical, clinically applicable ways to approach such requests must be developed in order to balance the fundamental principles at play. **Abstract (w. list of references):** <http://bit.ly/2xBU8aP>

Social work end-of-life care interventions for patients and their families in hospital

AUSTRALIAN SOCIAL WORK | Online – 12 March 2020 – As the majority of Australians receive end-of-life (EoL) care in hospitals, there is a need to examine the quality of social work interventions for dying patients and their families. Clinical data mining of 347 deceased patient’s files revealed different approaches to EoL interventions across one health network. Data demonstrate that although social workers are invaluable in providing emotional and practical assistance, greater awareness and education around evidence-based psychosocial bereavement risk and support may improve family support. Further development of theoretical and practical knowledge examining the interface between physical aspects of EoL care and social work intervention is warranted. Abstract: <http://bit.ly/2ILkolt>

When a child dies: A systematic review of well-defined parent-focused bereavement interventions and their alignment with grief- and loss theories

BMC PALLIATIVE CARE | Online – 12 March 2020 – This review identified fifteen well-defined bereavement interventions provided by regular healthcare professionals (HCPs) to support parents of seriously ill children both at the end of their child’s life and after death. All interventions were clustered into five overarching components of the intervention: 1) The acknowledgement of parenthood and the child’s life; 2) Establishing keepsakes; 3) Follow-up contact; 4) Education and information; and, 5) Remembrance activities. All five of these cover multiple key concepts derived from theory. HCPs can choose multiple interventions for different components to provide parents with a continuous form of bereavement care, aiding the transition that parents have to go through following their loss. Future research is needed on how this continuous support can be established, which time points are crucial for providing bereavement care, and how new interventions can be developed that align with this transition, and thus, ultimately, help parents in adjusting to their new reality. **Full text:** <http://bit.ly/38RA7tv>

Related:

- *BMC PALLIATIVE CARE* | Online – 12 March 2020 – ‘**Coping and wellbeing in bereavement: Two core outcomes for evaluating bereavement support in palliative care.**’ “Ability to cope with grief” and “Quality of life and mental wellbeing” were identified as two core outcomes. Coping related dimensions are categorised as: negative and overwhelming grief; communication and connectedness; understanding, accepting and finding meaning in grief; finding balance between grief and life going forwards; accessing appropriate support. Those relating to quality of life and wellbeing are categorised as; participation in work and/or regular activities; relationships and social functioning; positive mental wellbeing; and, negative mental and emotional state. **Full text:** <http://bit.ly/2xDjIw5>
- *JOURNAL OF LOSS & TRAUMA* | Online – 10 March 2020 – ‘**Complicated grief: How is it conceptualized by professionals.**’ Despite the proliferation of grief research, there is no consensus regarding the naming of grief that does not follow a typical trajectory. How a concept such as grief that has become complicated is named and understood will likely influence professionals’ engagement with it. Professionals defined complicated grief (CG) in ... a survey. Statistically significant differences were found regarding extended duration, being stuck, and the circumstances surrounding the death. The differences in professionals’ views of CG and its multidisciplinary nature underscore the need for consensus regarding its nomenclature and definition. **Abstract:** <http://bit.ly/33hBlrm>

Cont.

Noted in Media Watch 20 January 2020 (#649, p.10):

- *PROGRESS IN PALLIATIVE CARE* | Online – 12 January 2020 – ‘**Bereavement support: From the poor cousin of palliative care to a core asset of compassionate communities.**’ The negative consequences of bereavement and the disruption of social relationships put the impact of bereavement squarely into a public health perspective. Adopting and strengthening a compassionate communities approach is necessary, not only for end-of-life care for dying people but also for providing bereavement support. Many palliative care services continue to adopt an unhelpful standardised approach in offering bereavement support. So, who provides support to the bereaved? Who needs support and to what extent? **Abstract:** <http://bit.ly/2NktLLo>

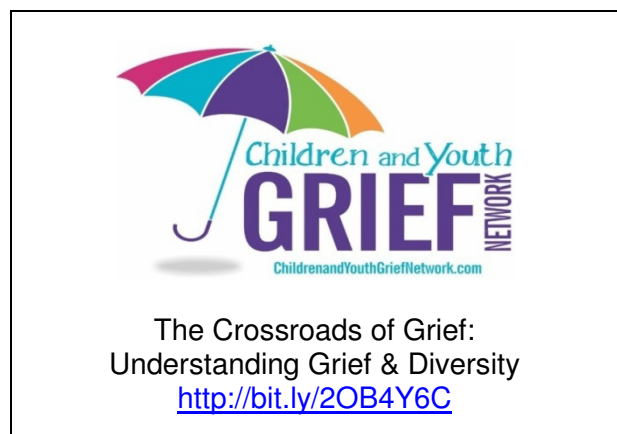
We all want to die in peace. So why don't we?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 13 March 2020 – Approximately 70% of Americans would prefer to die at home and avoid hospitalization or intensive care during the terminal phase of illness. Given the wish to die at home, it should follow the majority of Americans achieves their wish. However, recent data indicate 60% of people die away from home or hospice care. This article sets out to understand what makes it so difficult to attain what we aspire for in death and provide a starting point for change. Six elements which combine into a system driving non-peaceful death were identified (western culture, healthcare system, pharmaceutical industry, professionals, family and loved ones, patients themselves) and complemented with three additional factors entrenched in us as humans which make the system particularly difficult to overcome ((rational) decision-making, option framing, inability to change). Dying in peace is easier said than done because the cards are stacked against us and we seem to remain unaware of the breadth and depth at which continuing treatment is ingrained in our system. **Abstract:** <http://bit.ly/2Wf57kv>

The dying parent and dependent children: A nationwide survey of hospice and community palliative care support services

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 9 March 2020 – Limited information exists on how service providers are meeting family needs when a parent with dependent children is dying. A cross-sectional, web-based survey of adult 197 U.K. hospices was undertaken. Twenty-two per cent of hospices reported no formal processes for asking or documenting the presence of dependent children. Volunteers were an underused resource before parental death. Four themes characterised challenges in delivering support for families: 1) Emotional difficulties for families; 2) Practical and social difficulties for families; 3) Funding/resources; and, 4) Staff training/numbers. U.K. national end-of-life guidance for adults repeatedly acknowledges families should have honest, sensitive and well-informed conversations about dying, death and bereavement. Specifically, guidance states that dependent children require tailored support and, if patients with children want support, healthcare professionals should offer information and encourage family communication. To meet guideline requirements, this survey suggests support for children and families within service models needs to be more proactive; hospices appear

more attuned to addressing needs of children once they arise, rather than preventing them from arising. Although this was a survey of U.K. hospices it has relevance in an international context. The hospice movement is developing globally and shared understanding of support delivery in the context of families with dependent children can help meet emerging and growing service requirements across different countries. **Full text:** <http://bit.ly/39Fk3MS>



Cont.

Noted in Media Watch 20 January 2020 (#649, p.10):

- *PROGRESS IN PALLIATIVE CARE* | Online – 12 January 2020 – ‘**Bereavement support: From the poor cousin of palliative care to a core asset of compassionate communities.**’ The negative consequences of bereavement and the disruption of social relationships put the impact of bereavement squarely into a public health perspective. Adopting and strengthening a compassionate communities approach is necessary, not only for end-of-life care for dying people but also for providing bereavement support. Many palliative care services continue to adopt an unhelpful standardised approach in offering bereavement support. So, who provides support to the bereaved? Who needs support and to what extent? **Abstract:** <http://bit.ly/2NktLLo>

Hospice use among individuals with severe persistent mental illness

JOURNAL OF THE AMERICAN PSYCHIATRIC NURSES ASSOCIATION | Online – 6 March 2020 – Severe persistent mental illness (SPMI) currently affects an estimated 11.2 million adults in the U.S.. Affected individuals are known to experience inequities in care, and on average, they die earlier than individuals without SPMI. Currently, little is known about hospice use among individuals with SPMI, including what factors contribute to the use of hospice services. In this review of the available literature, three themes were identified: 1) Fragmentation of care; 2) Inadequate communication; and, 3) The need for advance care planning. These patterns indicated that multiple barriers to utilizing hospice care exist for individuals with SPMI when compared with the general population. By recognizing and addressing factors influencing the use of hospice care, as well as barriers to receiving hospice, improved provision of timely end-of-life care that is consistent with individuals’ preferences may be facilitated. **Abstract (w. list of references):** <http://bit.ly/3cInjc3>



Noted in Media Watch 20 January 2020 (#649, p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 January 2020 – ‘**Mental healthcare and palliative care: Barriers.**’ Psychological symptoms are common among palliative care (PC) patients with advanced illness, and their effect on quality of life can be as significant as physical illness. The demand to address these issues in PC is evident, yet barriers exist to adequately meet patients’ psychological needs. This article provides an overview of mental health issues encountered in PC, highlights the ways psychologists and psychiatrists care for these issues, describes current approaches to mental health services in PC, and reviews barriers and facilitators to psychology and psychiatry services in PC, along with recommendations to overcome barriers. **Abstract:** <http://bit.ly/35YIN1e>

Experiencing place identity and place belongingness at a children’s hospice: Parents’ perspectives

JOURNAL OF CHILD HEALTH CARE | Inprint – Accessed 8 March 2020 – Children’s hospices are key players in the provision of palliative care services for families with children with life-limiting conditions. However, evidence suggests that some of the negative terminology/language which surrounds the notions of palliative and hospice care may contribute to the lack of uptake of hospice services by families. This article reports on two elements of place bonding: parents’ experiences of place identity and place belongingness at a children’s hospice in a region in England. Focus groups were undertaken with 24 parents of children with life-limiting conditions accessing a children’s hospice. Despite initial reservations associated with the identity of the hospice, parents described how and why their view changed and therefore consequently how they were able to experience the hospice differently. The authors demonstrate how parents’ views of the identity of the hospice change and how the hospice becomes a place where parents experience a sense of belongingness. **Abstract:** <http://bit.ly/2TysFz7>



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Lack of awareness and common misconceptions about palliative care among U.S. adults: Insights from a national survey

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 10 March 2020 – Despite recent growth in palliative care (PC) programs PC remains underutilized. Studies suggest that patients and providers commonly associate PC with end of life, often leading to misconceptions and late referrals. PC knowledge was self-reported in response to: “How would you describe your level of knowledge about PC?” Level of misconceptions was based on a series of factual and attitudinal statements about PC. Among U.S. adults, 28.8% report knowing about PC, but only 12.6% report knowing what PC is and hold no misconceptions. Among those who report knowing about PC, misconceptions were common: 44.4% automatically think of death, 38.0% equate PC with hospice, 17.8% believe you must stop other treatments, and 15.9% see PC as giving up. **Abstract (w. list of references):** <http://bit.ly/2TLOtaJ>

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

JOURNAL OF PALLIATIVE CARE | In Print – Accessed 12 March 2020 – This article examines the intersection between masculinity, military culture, and hospice and palliative care (HPC). 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 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. **Abstract (via PubMed):** <http://bit.ly/38LljM6>

Palliative care advocacy: Why does it matter?

JOURNAL OF PALLIATIVE MEDICINE | Online – 9 March 2020 – Widespread unfamiliarity with the palliative care (PC) approach to serious health-related suffering challenges PC advocacy at all levels. Misunderstandings are pervasive throughout the United Nations system, national healthcare systems, the media, and the general public. Policymakers and providers who are somewhat familiar with PC stigmatize this relatively new public health approach as only appropriate for end of life, or only for cancer, etc. Such misunderstandings undercut public policy and limit service delivery to the private and charitable sectors, which can only meet a fraction of the growing global need. Evidence-based testimony by providers trained in basic PC, and service users who have benefited, can support recognition of the universal nature of the right. Success stories can assuage uninformed concerns about additional costs of integrating PC services in the context of hospital-based systems and ally widespread fears that associate essential PC medicines with illegal “drugs.” The International As-

sociation for Hospice & Palliative Advocacy Program and the organization, its board, and staff members will continue to provide support and guidance to all its stakeholders, including global, regional, and national PC organizations, members, policy makers, patients, caregivers, and professionals working to relieve suffering and improve the quality of life of millions of patients around the globe. **Full text:** <http://bit.ly/3aPIVlj>

Oxford Textbook of

Palliative Medicine

‘Communications with the Public,
Politicians, and the News Media,’
Synopsis: <http://bit.ly/2rHlIEl>

Cont.

Noted in Media Watch 2 July 2018 (#570, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2018;56(3):363-370. **'Reframing global palliative care (PC) advocacy for the sustainable development goal era: A qualitative study of the views of international PC experts.'** PC represents a value proposition that is not currently being maximized by advocacy. Participants strongly supported the rollout of national PC policies around the world to ensure PC attracts national funding streams and to attract global funding for PC. The absence of a global indicator for PC development is considered a severe impediment to the inclusion of PC within global efforts toward universal healthcare. Advocacy partnerships, using human rights approaches with economic frames are effective methods of influencing policymakers. **Full text:** <http://bit.ly/2TF43Vs>

Characteristics of hospices providing high-quality care

JOURNAL OF PALLIATIVE MEDICINE | Online – 6 March 2020 – The hospice market has changed substantially, shifting from predominantly not-for-profit independent entities to for-profit national chains. This study examined the association between hospice characteristics and care processes and performance on measures of hospice care quality: summaries of hospice-level performance on Consumer Assessment of Healthcare Providers & Systems (CAHPS) Hospice Survey measures (including communication, timely care, symptom management, emotional and spiritual support, respect, training families, overall rating, and willingness to recommend) and Hospice Item Set (HIS) measures (including pain screening and assessment, dyspnea screening and treatment, bowel regimen for patients on opioids, discussion of treatment preferences, and beliefs/values addressed). Of the 2,746 hospices that met public reporting requirements, 5.6% were in the top quartile of both CAHPS and HIS performance. Characteristics associated with being in the top quartile for CAHPS included being a non-profit and non-chain or government hospice, smaller size, and serving a rural area. Characteristics associated with being in the top quartile for HIS included being in a for-profit chain, larger size, and having <40% of patients in a nursing home. Providing professional staff visits in the last two days of life to a higher proportion of patients was

associated with hospices being in the top quartile of HIS and in the top quartile of CAHPS. Hospice characteristics associated with strong performance on HIS measures differ from those associated with strong performance on CAHPS measures. Providing professional staff visits in the last two days of life is associated with high performance on both quality domains. **Abstract:** <http://bit.ly/2THm8lQ>

Differences of quality in end-of-life care across settings: Results from the U.S. National Health & Aging Trends Study of Medicare Beneficiaries

JOURNAL OF PALLIATIVE MEDICINE | Online – 9 March 2020 – More than 2.5 million older Americans die each year. Place of residence in which dying patients receive care plays a crucial role in the quality of end-of-life care (EoLC). This study aimed to compare proxies' overall rating and ratings for 13 indicators across five major domains of EoLC by place of residence in the last month of decedents' lives. Hospice recipients, regardless of setting, were more likely to experience pain and talk about religion in the last month of life; families of patients without hospice in residential care settings were more likely to report not being kept informed; proxies of patients living in private residences with hospice care reported higher overall ratings. Among hospice recipients, those living in private residences were more likely to be treated with respect. **Abstract:** <http://bit.ly/3cOBooz>



[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>

Pallium Canada’s curriculum development model: A framework to support large-scale courseware development and deployment

JOURNAL OF PALLIATIVE MEDICINE | Online – 6 March 2020 – The need to improve access to palliative care (PC) across multiple settings and disease groups has been identified. This requires equipping healthcare professionals from many different professions, including physicians and nurses, among others, with basic PC competencies... Pallium Canada’s Curriculum Development Framework supports the development, deployment, and dissemination, on a large scale, of multiple courses targeting healthcare professionals across multiple settings of care and disease groups. The Framework is made up of eight phases: 1) Concept; 2) Decision; 3) Curriculum planning; 4) Prototype development; 5) Piloting; 6) Dissemination; 7) Language and cultural adaptation; and, 8) Ongoing maintenance and updates. Several of these phases include iterative cyclical activities. The Framework allows multiple courses to be developed simultaneously, staggered in a production line with each phase and their corresponding activities requiring different levels of resources and stakeholder engagement. The Framework has allowed Pallium Canada to develop, launch, and maintain numerous versions of its Learning Essential Approaches to Palliative Care (LEAP) courses concurrently. It leverages existing LEAP courses and curriculum materials to produce new LEAP courses, allowing significant efficiencies and maximizing output. This article describes the framework and its various activities, which could be very useful for other jurisdictions undertaking the work of developing education programs to spread the PC approach across multiple settings, specialties, and disease groups. **Abstract:** <http://bit.ly/33auupg>

Initial spiritual screening and assessment: Five things to remember

KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE, 2020;23(1):1-4 To deliver holistic and person-centered palliative care (PC), the spiritual dimension must also be assessed. However, many nurses do not screen for or assess patient spirituality. This article presents five things that PC nurses can consider in order to improve their spiritual screening and assessment practices: 1) Understand that spirituality is manifest in a myriad of ways and is not the same thing as religiosity; 2) Screen for spiritual distress, and then later conduct a spiritual history or assessment; 3) Remember that spirituality is not just something to assess upon admission; 4) Know that there are many ways to assess spirituality (it is not merely how a patient verbally responds to a question about spirituality or religiosity; and, 5) Remember that assessment can also be therapeutic. **Abstract:** <http://bit.ly/39PAjuZ>

N.B. Click on pdf icon to access full text. Additional articles on spirituality noted in 20 January 2020 issue of Media Watch (#649, p.6).

“Kipal, the who what how game in palliative care”: An educational board game in palliative care

MÉDECINE PALLIATIVE | Online – 14 March 2020 – “Kipal, the game of who what how in palliative care” is an educational tool developed by a nurse and a doctor, members of a mobile palliative care (PC) team at the Vienne Hospital in France. Through the creation of fictitious and evolving patient cases during the game, participating caregivers can interactively learn about various topics related to PC. The expected benefits are a real involvement of the learners becoming actors of their own training, the de-dramatization of PC in general, the identification of palliative situations and to highlight the variety of PC by the wealth of the available scenarios. Indeed, Kipal contains 16 short clinical situations from various specialties and an additional 46 “event” cards (that add a clinical, psychological, social, or family-linked event) and 62 “suggestion” cards (that describe human and technical resources available) that could be associated countlessly with each game of cards. This tool is designed to be used by PC professionals during their training sessions of non-specialized caregivers who take care of PC patients. In the future, variants may be developed to suit a wider audience (including pediatrics teams, nursing home teams). Funded by the Fonds pour les soins palliatifs and approved by the Société française d’accompagnement et de soins palliatifs (SFAP), 250 Kipal games were distributed during the French congress of PC organized by the SFAP and the Fédération francophone internationale de soins palliatifs in 2019. **Abstract:** <http://bit.ly/39RVhcz>



N.B. French language article.

Religious observance and perceptions of end-of-life care

NURSING INQUIRY | Online – 12 March 2020 – This study examines the impact of the level of religious observance on the attitudes toward end-of-life (EoL) decisions and euthanasia of Jews in Israel – where euthanasia is illegal – as compared to Jews living in the U.S., in the states where euthanasia is legal. A self-reporting questionnaire on religiosity and personal beliefs and attitudes regarding EoL care and euthanasia was distributed, using a convenience sample of 271 participants from Israel and the U.S.. Findings show that significant differences were found in attitudes between Jews of different levels of religious observance with respect to patient autonomy, right-to-die with dignity, and dying in familiar and supportive surroundings. The U.S. and Israeli Jews have similar knowledge regarding EoL care and expressed similar attitudes and perceptions toward the issues of authority of medical staff and religious figures and patient's autonomy. Findings indicate that the level of religious observance has more potency in shaping their attitudes and perceptions of EoL decisions than the state law. The authors conclude by discussing the implications of their findings with regard to multicultural health systems and providing practical recommendations. **Abstract:** <http://bit.ly/2W9VXWy>

Paediatric palliative care research *has* come of age

PALLIATIVE MEDICINE, 2020;34(3):259-261. The collection of articles in this issue suggests that paediatric palliative care research *has* come of age [see sidebar]. That is, high-quality investigation to benefit seriously ill children and their families is being conducted across the globe. At the same time, we have a long way to go in research, care and treatment. Indeed, many of the publications featured here show ongoing high suffering in children, their families and the clinicians who care for them and remind us of the work before us if we are to meet the challenge of reducing suffering. Attaining that bar will require development and implementation of high-quality interventions which are grounded both in a thorough, robust understanding of the problems children, parents and clinicians face and in the complexity of the situations in which they are delivered. The interventions we develop and deliver require attention to the multiple factors that underpin the problems they are designed to ameliorate. That said, we must not allow our pursuit of the perfect, the ideal, to overtake a trial of the good. **Full text:** <http://bit.ly/2TSKpVT>



Portuguese Patient Dignity Question: A cross-sectional study of palliative patients cared for in primary care

PALLIATIVE & SUPPORTIVE CARE | Online – 10 March 2020 – The Patient Dignity Question (PDQ) is a clinical tool developed with the aim of reinforcing the sense of personhood and dignity, enabling health-care providers (HCPs) to see patients as people and not solely based on their illness. Twenty participants were included in this cross-sectional study. 75% were male; average age was 70 years old. Patients found the summary accurate, precise, and complete; all said that they would recommend the PDQ to others and wanted a copy of the summary placed on their family physician's medical chart. They felt the summary heightened their sense of dignity, considered it important that HCPs have access to the summary and indicated that this information could affect the way HCPs see and care for them. **Abstract (w. list of references):** <http://bit.ly/3cMFLR2>

Reflections on the integration of a narrative medicine and mindfulness program in hospice and palliative care

PROGRESS IN PALLIATIVE CARE | Online – 14 March 2020 – By 2060, almost 25% (98 million) of the population [in the U.S.] is expected to be aged 65 or older. Healthcare professionals (HCPs) who provide hospice and palliative care (PC) are over-tasked and demonstrate symptoms of burnout. Narrative medicine and mindfulness interventions create meaningful connections with patients, improve the delivery of patient-centered care, and enhance the health of the caregivers. HCPs in hospice and PC settings were invited to participate in a study to evaluate the impact of narrative medicine or mindfulness on measures of burnout and empathy. Participants completed baseline and 12-week post-intervention surveys of burnout and empathy, as well as weekly journals of their experience. Mean overall scores for depersonalization were significantly reduced at 12-week post-intervention. There were no significant changes in emotional exhaustion or empathy compared to baseline. This brief, weekly intervention may be beneficial for both patients and HCPs in the hospice and PC setting. **Abstract:** <http://bit.ly/2TOxjJo>

Improving palliative and end-of-life care for rural and remote Australians

PUBLIC HEALTH RESEARCH & PRACTICE | Online – 10 March 2020 – Recent reports highlight an inconsistent provision of palliative and end-of-life care (EoLC) across Australia, particularly in regional, rural and remote areas. A palliative approach to care is crucial in rural and remote Australia where there is a reliance for such care on generalist providers amid the challenges of a limited workforce, poorer access, and vast geography. This article describes the development and implementation of the Far West New South Wales (NSW) Palliative & End-of-Life Model of Care, a systematic solution that could drive improvement in the provision of a quality palliative approach to care and support from any clinician in a timely manner, for patients, their families and carers anywhere. The Model is one example of a fit-for-purpose and systematic response to enhance the local provision of a palliative approach to EoLC in rural and remote NSW. It responds to findings that clinicians require a model to guide the delivery of palliative care and is enhanced with direction from evidence-based practice. It functions with leadership from a Specialist Palliative Care Service which can drive evidence-based care in the generalist space by sharing knowledge and tools to ensure a current, effective and supported palliative approach. Despite the challenges of rurality, and a paucity of rural and remote palliative research, the experience in Far West Local Health District demonstrates that it is possible to provide a patient-centred, needs-based and high-quality palliative approach to care at home (or as close to home as possible), in accord with the wishes of patients and their families. The Model offers a systematic solution that could drive improvement in the provision of a quality palliative approach to care and support for patients, their families and carers anywhere. **Full text:** <http://bit.ly/335nQR4>

N.B. Additional articles on the provision and delivery of palliative and EoLC in rural and remote regions of Australia noted in 9 December 2019 issue of Media Watch (#643, p.16).



Prison Hospice: Backgrounder

Updated 03.15.2020

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report can be downloaded/viewed on the Palliative Care Network website at: <http://bit.ly/2RdegnL>

Photo: Lori Waselchuk. Philadelphia, PA



Closing the Gap Between Knowledge & Technology

<http://bit.ly/2DANDFB>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *SOCIAL & POLICY ADMINISTRATION* | Online – 3 March 2020 – ‘**Value-based issues and policy change: Medical assistance in dying in four narratives.**’ In 2014, Québec became the first province in Canada to allow medical assistance in dying (MAiD) by adopting the Act Respecting End-of-Life Care. This was, and still is, an important policy change. It involves a singular and highly moral issue that generated debates spanning over a longer period than that specific to the law’s development and adoption. Using French and English newspapers’ renderings of these debates in Québec between 2005 and 2015, this study deconstructs MAiD’s journey in the province into four periods, each characterized by a specific narrative: 1) Flexible precaution; 2) Legal hypocrisy; 3) Accountability imperative; and, 4) Ineluctable adaptation. These four narratives allow a better understanding of MAiD’s framing process as they reveal the underlying rationales of three overarching frames covering the 2005-2015 period: 1) The legal frame; 2) The social progress frame; and, 3) The service provision frame. **Abstract:** <http://bit.ly/2THfuMq>

Publishing Matters

To ensure the quality of peer reviewed research introduce randomness

LONDON SCHOOL OF ECONOMICS & POLITICAL SCIENCE | Online – Accessed 11 March 2020 – The present publication process in academia is characterised by a “tyranny of top journals”. There are many biases in the review process. Evaluations by referees tend to be inconsistent, and the outcome of the review process only predicts the future impact of a scholarly contribution to a low degree. Moreover, empirical research has documented that to evaluate an article published in a “good” journal to be a “good” article is wrong in about two-thirds to three-quarters of all cases, due to the heavily skewed distribution of citations, i.e. certain articles accounting for the majority of citations in a journal. This is true for both short citation windows and five-year spans. Nevertheless, top publications continue to have a powerful influence on promotion and tenure decisions. How to stop this obsession with top journal publications? We advance a radical proposal, namely focal random selection of articles: When reviewers agree on the excellent quality of a paper, it should be accepted. Papers perceived unanimously as valueless are rejected immediately. Papers that are evaluated differently by the referees should be selected randomly for publication. Why random selection of contributions to which the referees do not agree? This procedure reduces the “conservative bias”, i.e. the bias against unconventional ideas. Where there is uncertainty over the quality of a contribution, referees have little evidence to draw on in order to make accurate evaluations. However, unconventional ideas may well yield high returns in the future. Under these circumstances a randomised choice among the unorthodox contributions is advantageous. **Full text:** <http://bit.ly/339tSjC>

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

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Cont.

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[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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