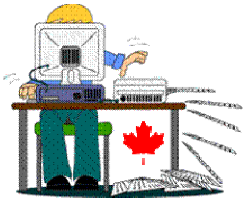
Media Watch...

*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.*

14 May 2018 Edition | Issue #563



Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'Palliative care volunteerism across the healthcare system: A survey study' (p.9), in *Palliative Medicine*.

Canada

Palliative care approach emphasized by Doctors Nova Scotia

NOVA SCOTIA | Global TV News (Halifax) – 11 May 2018 – Doctors Nova Scotia is emphasizing a palliative approach to care for patients in Nova Scotia. "Say you're diagnosed with COPD, a chronic lung disease. It can be something that is going to shorten your life, so we probably should be starting to think, even early on, about some aspects that, if this is going to shorten your life, what discussions do we need to have, and what things do you need to think about with regards to some of your goals of care? What kind of things would you like to see happen over time?" Dr. David Henderson, a co-chair of palliative medicine for the organization, said in an interview... The organization recently released a position paper on the topic with 10 recommendations on the matter.[1] https://goo.gl/zZNnPo

Specialist Publications

'Perceived barriers and facilitators to goals-of-care discussions in the emergency department: A descriptive analysis of the views of emergency medicine physicians and residents' (p.5), in *Canadian Journal of Emergency Medicine*.

'Wiisokotaatiwin: Development and evaluation of a community-based palliative care program in Naotkamegwanning First Nation' (p.10), in *Rural & Remote Health*.

'Canadian and Dutch doctors' roles in assistance in dying' (p.12), in *Canadian Journal of Public Health*.

1. 'Supporting the Palliative Care Approach: Recommendations for Nova Scotians,' Doctors Nova Scotia, 2018 Position Paper. **Download/view at:** https://goo.gl/eUferX

Corrections & Clarifications

'Palliative care inadequate for coming "silver tsunami" concludes Hamilton report'

The 7 May 2018 issue of Media Watch (#562) included a report (on p.1) on end-of-life care in Hamilton, Ontario, a case study by the faith-based think tank, Cardus. The case study was a companion piece to Cardus' 'Renewing end-of-life." The latter also included 'Case Study: Ottawa,' which can be downloaded/viewed at: https://goo.gl/njhsya

Health Canada launches consultations on palliative care framework

HEALTH CANADA | Online – 7 May 2018 – Health Canada has announced a public consultation on a framework for palliative care (PC) in Canada. Canadians and interested stakeholders are invited to share their views online until 13 July 2018.[1] The federal government will consult directly with provinces, territories, PC providers, people living with illness, caregivers, and other expert stakeholders. The comments received during these consultations will help inform the development of the framework for PC, which will be tabled in Parliament by 13 December 2018. https://goo.gl/aRdAaQ

1. 'Consultation on palliative care,' Health Canada: https://goo.gl/HD3zss

N.B. Articles on the evolution of a national palliative care strategy for Canada noted in the 1 January 2018 issue of Media Watch (#544, pp.18-19). Articles on the passage of Bill C-277, a 'Framework on Palliative Care in Canada Act,' noted the 18 December 2017 issue of Media Watch (#543, pp.1-2). For a listing of nine key studies on end-of-life care in Canada, published between 1995-2014 see the 22 December 2014 issue of Media Watch (#389, p.4). See also 'Right to Care: Palliative care for all Canadians,' Canadian Cancer Society, December 2015, noted in the 18 January 2016 issue of Media Watch (#445, p.1).

U.S.A.

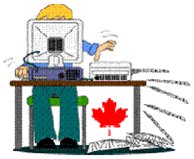
Unintended consequences of addressing the opioid crisis

POLITICO | Online – 8 May 2018 – The push for fewer opioid prescriptions at lower doses and for shorter periods has increased suffering for some pain patients, including those near the end of life (EoL). There's been a lot of research lately on what opioids don't work for – but there's no doubt that they can be essential for many patients nearing the EoL, or suffering metastatic cancer. Centers for Disease Control prescribing guidelines and state laws limiting prescriptions generally don't restrict opioids for these patients – but hospice and palliative care physicians report that their patients are having a very difficult time getting the pain control they need. "Almost every patient I have prescribed for recently has either a) run into pharmacies that no longer carry common opioids; b) cannot receive a full supply; and, c) worst of all had their mail order pharmacy refuse to fill or have had arbitrary and non-science based dose or pill limits imposed," said Sean Morrison, of the geriatrics and palliative medicine department at the Icahn School of Medicine at Mount Sinai. https://goo.gl/wP3Brg

Specialist Publications

'Clinicians' perceptions of medication errors with opioids in cancer and palliative care services: A priority setting report' (p.11), in *Supportive Care in Cancer.*

N.B. Reports on the consequences of stricter controls on opioid use in the U.S., in the context of hospice and palliative care noted in the 9 April 2018 (#558, p.3).



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://goo.gl/5CHoAG

Beyond the person in the bed

OHIO | *The Logan Daily News* – 5 May 2018 – There is one distinction that makes hospice different from other areas of medicine. That distinction is the Medicare requirement stating that volunteers must provide some of the day-to-day administrative and/or direct patient contact services. In fact, it is specific that the total of the volunteers' efforts must be in an amount that, at a minimum, equals 5% of the total patient care hours of all paid hospice employees and contact staff. Therefore, volunteers aren't just a nice idea, they are a requirement. This idea behind engaging volunteers to be a part of hospice compassion is to foster a feeling of normalcy with the person being cared for. In other words, by being involved the volunteer's presence helps to remove some of the sterile atmosphere of medical care. https://goo.gl/RCcRhA

Specialist Publications

'Measuring the impact of the home health nursing shortage on family caregivers of children receiving palliative care' (p.7), in *Journal of Hospice & Palliative Nursing.*

'Palliative care volunteerism across the healthcare system: A survey study' (p.9), in *Palliative Medicine.*

'Subduing attitude polarization?: How partisan news may not affect attitude polarization for online publics' (p.12), in *Politics and the Life Sciences*.

International

China's palliative care system gives little comfort to the dying

CHINA | Sixth Tone (Shanghai) – 6 May 2018 – The rapid development and deployment of medical sciences in China has led to a popular misconception in the country that medicine is an omnipotent and certain science. But in reality, medicine relies heavily on probability, educated guesswork, and compromise. Even today, we lack sufficient understanding of many diseases. Most diseases are not yet fully curable, and in many cases, we can only slow their progression. This is the backdrop to a growing focus among the Chinese medical community on palliative care (PC). The Quality of Death Index, a measure of PC quality in 80 countries around the world ... compares the supply of PC with the demand for it.[1] While the top of the list is dominated by wealthy Western countries with strong public health systems, the index ranked China 71st for overall quality of death and 69th for its palliative and health care environment. It also showed that terminally ill patients in China are unlikely to receive PC. Those who do are likely to be city dwellers, as the majority of Chinese hospices are concentrated in urban areas. The country also lacks fully equipped PC units. Most hospices suffer from shortages of psychologists, social workers, and volunteers. Medical schools rarely teach PC to students, and there are few specialized accreditations in China that cover end-of-life care. https://goo.gl/Sutw86

Specialist Publications

'Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the U.S.: A comprehensive review' (p.11), in *BMC Palliative Care.*

'Definition of terms used in limitation of treatment and providing palliative care at the end of life: The Indian Council of Medical Research Commission report' (p.6), in *Indian Journal of Critical Care Medicine.*

'Palliative care in the global setting: American Society of Clinical Oncology resource-stratified practice guideline' (p.7), in *Journal of Global Oncology*.

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit (London, U.K.), October 2015. (See 'Case study: China – growing awareness,' p.20-21.) Commissioned by the Lien Foundation of Singapore. [Noted in the 12 October 2015 issue of Media Watch (#431, p.6)] https://goo.gl/zXrniA

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SPAIN | *The Local Spain* – 10 May 2018 – **'Spain takes tentative first step to legalising euthanasia.'** Spain's lower house voted in favour of examining a bill on legalising euthanasia, a first in the country even if there will likely be major opposition as it weaves its way through parliament. Lawmakers voted 173 against 135 – and 32 abstentions – to examine the bill, which was originally drafted by Catalonia's regional assembly. This is the first time that a bill aimed at legalising euthanasia makes it past this first hurdle after previous attempts failed... It seeks to modify part of Article 143 of Spain's penal code, which currently bans anyone from causing or cooperating with the death of another person suffering from "a serious, terminal illness or one that causes serious, permanent ailments that are difficult to endure." The bill would make it legal for a person to cause or help cause the "reliable, peaceful, painless death" of another suffering from those problems if they "specifically, freely and unequivocally" ask for it. Currently in Spain, people with incurable diseases only have the option to refuse treatment. https://goo.gl/d5Tofr

Specialist Publications

End-of-life care in Ireland

Development and initial psychometric properties of a questionnaire to assess competence in palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 6 May 2018 – The results of this study provide a baseline assessment of competence in palliative care (PC) among physicians in Ireland. The study also creates a reference for future evaluation of the impact of education on PC competence. The findings suggest that attitudes are generally positive, but there is scope for improvement. Although behavior toward and knowledge of PC were evaluated less positively, a positive correlation between all three attributes – knowledge, attitudes and behavior – was demonstrated. The tool used in this study was mapped to a competence framework developed for PC in Ireland. This provided a novel way to understand current competence in PC in physicians. The novelty of this study is a key strength; however, a limitation of this study is the reliance on self-reported competence, recognizing the possibility of social desirability bias. However, the range of scores evident would suggest variation in the data. That said, we would argue that the next step would be to engage in an objective assessment of physician's competence in PC to validate the scale. **Full text:** https://goo.gl/WfMyMp

Journal Watch

'Bibliometric analysis of palliative care-related publication trends during 2001 to 2016' (p.12), in *American Journal of Hospice & Palliative Care.*

Corrections & Clarifications

'The codesign of an interdisciplinary team-based intervention regarding initiating palliative care in pediatric oncology'

The 16 April 2018 issue of Media Watch (#559) included an article (on p.13) published in *Supportive Care in Cancer* in which the authors indicated that "the procedures and results of this project will be posted online so that other institutions can use them as a model for developing similar interventions appropriate for their needs." These can now be downloaded/viewed at: https://goo.gl/jvvyft

IPCRC.NET International Palliative Care Resource Center

Back Issues of Media Watch
http://goo.gl/frPgZ5

Perceived barriers and facilitators to goals-of-care discussions in the emergency department: A descriptive analysis of the views of emergency medicine physicians and residents

CANADIAN JOURNAL OF EMERGENCY MEDICINE | Online – 8 May 2018 – The majority of participants reported feeling comfortable and adequately trained to conduct goals-of-care (GOC) discussions. However, they identified time constraints, environmental factors, and patient expectations as barriers. Fifty-four percent of respondents believed that it was primarily the responsibility of admitting services to conduct GOC discussions. This study suggests that dedicated emergency department (ED) resources for palliative care (PC), such as a PC ED pathway, and addressing structural factors, such as a way to dedicate time and private space to GOC discussions, would be promising avenues for improvement. **Abstract (inc. list of references):** https://goo.gl/ZLcxNx

Noted in Media Watch 23 April 2018 (#560, p.10):

- *EMERGENCY MEDICINE AUSTRALASIA* | Online – 16 April 2018 – **'Testing a new form to document "goals-of-care" discussions regarding plans for end-of-life care for patients in an Australian emergency department.'** There is limited literature to inform the content and format of goals-of-care forms for use by doctors when they are undertaking these important conversations. This study supports having a goals-of-care form in emergency medicine. The ideal contents of the form, however, was not determined. **Abstract:** https://goo.gl/qnpX17

An invitation to grief in the family context

DEATH STUDIES | Online – 7 May 2018 – Grief is a family affair, yet is commonly viewed as an individual phenomenon. As an international, interdisciplinary team, the authors explore grief within a family context across theoretical, research, practice, and educational domains. Families are complex and working with this complexity is challenging but necessary for a holistic view of grief. They therefore encourage an increased focus on theorizing, researching, practicing, and educating using innovative approaches to address the complexities of grief within the context of families. Learnings from within each domain will affirm and enhance the development of family level thinking and approaches. **Abstract:** https://goo.gl/x77aMZ

Development and implementation of a pediatric palliative care program in a developing country

FRONTIERS IN PUBLIC HEALTH | Online – Accessed 7 May 2018 – Globally, 98% of children who need palliative care (PC) live in low- or middle-income countries, where there are very few PC services available. In this report, the authors describe the key steps and practical considerations to develop and implement a pediatric PC consultation service at a tertiary hospital in a resource limited setting in Dhaka, Bangladesh. The crucial aspects of this pilot project included raising awareness among hospital administrators and clinical staff, providing education and training for hospital staff, implementing a clinical PC service, and collecting data to define the PC needs of children with cancer. The use of volunteers to provide play, art, and music was a simple and effective way to expand the PC supports in which this small pediatric PC team was able to provide. The authors discuss the practical implications, lessons learned, and limitations of their approach under four key aspects of the project. **Full text:** https://goo.gl/wuoGST

THE CHILDREN'S PALLIATIVE CARE
INITIATIVE IN BANGLADESH

Noted in Media Watch 26 February 2018 (#552, p.8):

- *CHILDREN* | Online – 19 February 2018 – **'Paediatric palliative care in resource-poor countries.'** Globally it is estimated that 21.6 million children need access to palliative care (PC), with 8.2 needing specialist services. PC has been identified as important within the global health agenda, e.g., within universal health coverage, and a recent *Lancet* commission report recognised the need for paediatric PC.[1] However, a variety of challenges have been identified to paediatric PC development globally such as access to treatment, access to medications. **Abstract:** https://goo.gl/dBTGi7

    1. 'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,' *The Lancet*, published online 12 October 2017. [Noted in the 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** https://goo.gl/i7r9M1

Cont.

Related

- *BMC PALLIATIVE CARE* | Online – 8 May 2018 – **'How do professionals assess the quality of life of children with advanced cancer receiving palliative care, and what are their recommendations for improvement?'** Participants in this study reported that the lack of planned or systematized procedures in regard to quality of life (QoL) in their care practices may lead to disagreements on the QoL of the same child in the same situation. To address these issues, professionals recommend interdisciplinary communication, involving the child and his/her family in the assessment process, developing training specific to pediatric palliative care (PPC), and stress the need to create a tool to measure the QoL of children in the context of PPC specifically. **Full text:** https://goo.gl/GHhr22

It's about time for palliative care in humanitarian emergencies

HUMANITARIAN HEALTH DIGEST | Online – Accessed 11 May 2018 – The Syrian crisis is a watershed moment in humanitarian action. It has shed a light on a myriad of complex issues and gaps, many relating to the protracted nature of conflict and displacement outside of camp settings in middle-income countries. The importance of palliative care (PC) in such contexts is critical, but rarely discussed, never mind addressed. It's time to provide holistic PC in humanitarian emergencies consisting of pain management and psychosocial support, including social and spiritual aspects. In a recent article the authors undertake an exploratory qualitative study of the gaps and challenges of providing such long-term, specialized and continuous services to refugees with life-limiting conditions.[1] **Full text:** https://goo.gl/DZUKxX

1. 'The role of palliative care in addressing the health needs of Syrian refugees in Jordan,' *Medicine, Conflict & Survival*, 2018;34(1):19-38. **Abstract:** https://goo.gl/uHNYML

N.B. Additional articles on the provision of palliative care during humanitarian crises or natural disasters noted in the 7 May 2018 issue of Media Watch (#562, p.11).

Definition of terms used in limitation of treatment and providing palliative care at the end of life: The Indian Council of Medical Research Commission report

INDIAN JOURNAL OF CRITICAL CARE MEDICINE, 2018;22(4):249-262. Indian hospitals, in general, lack policies on the limitation of inappropriate life-sustaining interventions at the end of life. To facilitate discussion, preparation of guidelines and framing of laws, terminologies relating to the treatment limitation, and providing palliative care at the end-of-life care (EoLC) need to be defined and brought up to date. This consensus document on terminologies and definitions of terminologies was prepared under the aegis of the Indian Council of Medical Research. Twenty-five definitions related to the limitations of treatment and providing palliative care at the end of life were created by reviewing existing international documents and suitably modifying it to the Indian socio-cultural context by achieving national consensus. Currently, in India, the usage of the terms across professional, legal, and social domains has lacked standardization and clarity. This has proved to be a significant barrier to building consensus for public policy relating to EoLC... **Full text:** https://goo.gl/q8j8Ey

"It's a nice place, a nice place to be." The story of a practice development programme to further develop person-centred cultures in palliative and end-of-life care

INTERNATIONAL PRACTICE DEVELOPMENT JOURNAL | Online – 16 May 2018 – The authors provide a detailed account of the processes and outcomes of a programme specifically designed to develop a person-centred culture in a palliative and end-of-life care service. The programme used a transformational practice development approach for the development of a person-centred culture and a framework for human flourishing as a means of analysing processes and outcomes. The programme demonstrated the importance of person-centred cultures for sustainable person-centred care; the creation of such cultures is imperative if sustainable person-centred care is to be made a reality. Human flourishing is a desirable moral goal in organisations, recognising the need for the personhood of all persons to be respected. If we are to move beyond the rhetoric of person centredness and truly embrace its values, then the continuous articulation of "patient-centredness disguised as person-centredness" needs to end. **Full text:** https://goo.gl/hKBqhT

Palliative care in the global setting: American Society of Clinical Oncology resource-stratified practice guideline

JOURNAL OF GLOBAL ONCOLOGY | Online – 8 May 2018 – The purpose of this new resource-stratified guideline is to provide expert guidance to clinicians and policymakers on implementing palliative care (PC) of patients with cancer and their caregivers in resource-constrained settings and is intended to complement the Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology (ASCO) Clinical Practice Guideline Update of 2016. The recommendations help define the models of care, staffing requirements, and roles and training needs of team members in a variety of resource settings for PC. Recommendations also outline the standards for provision of psychosocial support, spiritual care, and opioid analgesics, which can be particularly challenging and often overlooked in resource-constrained settings. The guideline is intended to complement but not replace local guidelines. **Full text:** https://goo.gl/Hydd43

Related

- *PALLIATIVE MEDICINE* | Online – 9 May 2018 – **'Differences between early and late involvement of palliative home care in oncology care: A focus group study with palliative home care teams.'** Information on whether existing models of integrated care are applicable to the home care system and how working procedures and skills of the palliative care teams might require adaptation is missing. In this study, differences were found concerning 1) reasons for initiation, 2) planning of care process, 3) focus on future goals versus problems, 4) opportunity to provide holistic care, 5) empowerment of patients, and 6) empowerment of professional caregivers. A shift from a medical approach to a more holistic approach is the most noticeable. **Full text:** https://goo.gl/7Vvr8B

Measuring the impact of the home health nursing shortage on family caregivers of children receiving palliative care

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2018;20(3):260-265. The national nursing shortage [in the U.S.] translates into a gap in home nursing care available to children with complex, chronic medical conditions and their family caregivers receiving palliative care (PC) consultations. A total of 38 home health nursing surveys were completed by families receiving pediatric PC consultation services at a free-standing children's hospital in the Midwest. The gap in the average number of nursing hours allotted versus received was 40 h/wk per family, primarily during evening hours. Parents missed an average of 23 hours of employment per week to provide hands-on nursing care at home, ranking stress regarding personal employment due to nursing shortage at 6.2/10. Families invested an average of 10 h/mo searching for additional nursing coverage and often resorted to utilizing more than 6 different home nurse coverage personnel per month. Families reported multiple delays to hospital discharges (mean, 15 days per delay) due to inability to find home nursing coverage. **Abstract:** https://goo.gl/abm1ZX

Related

- *JOURNAL OF HEALTH & HUMAN SERVICES ADMINISTRATION*, 2018;41(1):26-51. **'Patient centered care and turnover in hospice care organizations.'** This study examines whether nursing turnover is affected as organizations respond to environmental pressures for increased patient-centered care (PCC). Does the use of patient-centered approaches to meeting client needs reduce turnover in the nursing staff? Using hierarchical regression to analyze organizational, market, and personnel data from 695 hospices across the U.S., this study finds innovative PCC practices are significantly related to reduced nursing turnover. **Abstract:** https://goo.gl/Loj7cJ

N.B. Additional articles on the palliative care workforce in the U.S. noted in the 1 January 2018 issue of Media Watch (#544, p.4).

Ethical implications of medical crowdfunding: The case of Charlie Gard

JOURNAL OF MEDICAL ETHICS | Online – 4 May 2018 – In the case of Charlie Gard, an infant born with encephalomyopathic mitochondrial DNA depletion syndrome, crowdfunding was used to finance experimental nucleoside therapy. Although this treatment was not provided in the end, the authors argue that the success of the Gard family's crowdfunding campaign reveals a number of potential ethical concerns. First, this case shows that crowdfunding can change the way in which communal healthcare resources are allocated. Second, within the U.K.'s National Health Service, healthcare is ostensibly not a market resource; thus, permitting crowdfunding introduces market norms that could commodify healthcare. Third, pressures inherent to receiving funds from external parties may threaten the ability of patients-cum-recipients to voluntarily consent to treatment. The authors conclude that while crowdfunding itself is not unethical, its use can have unforeseen consequences that may influence conceptions of healthcare and how it is delivered. **Abstract:** https://goo.gl/o6Ehin

Addressing religious or cultural opposition to brain death diagnosis

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2018;20(3):252-259. In 1968, the neurologic or "brain death" standard for declaration was introduced as an accepted standard for declaration of death in hospitals where heartbeat and breathing are being sustained by technology, but functions of the brain, including the brain stem, have ceased. For many people, this accepted ethical, legal, and medical definition of death by neurologic standards can seem to blur the line between life and death as the heart is still beating, the lungs are still moving air albeit by mechanical ventilation, and the body is still warm. As experts in end-of-life care (EoLC), hospice and palliative care nurses must be knowledgeable about declaration of death by neurologic criteria, understand beliefs that do not support the concept, and collaborate with the health care team in providing compassionate EoL. **Abstract:** https://goo.gl/j6Jsfm

N.B. Additional articles on defining "brain death" noted in the 23 April 2018 issue of Media Watch (#560, p.11).

Related

- *JAMA INTERNAL MEDICINE*, 2018;319(18):1859-1860. **'Defining death – making sense of the case of Jahi McMath.'** Clearly distinguishing between the living and the dead is an essential function in any society, necessary for determining when people may be buried, when their wills may be executed, when efforts to keep them alive may be terminated, and when they may donate their organs, among other issues. The recent and ongoing case of Jahi McMath has raised some doubts about how this distinction is made in the U.S. **Abstract:** https://goo.gl/1wCPAv

  N.B. Additional articles on the Jahi McMath case noted in the 16 April 2018 issue of Media Watch (#559, p.9).

- *NEUROLOGY*, 2018;90(18):857-859. **'Right brain: Withholding treatment from a child with an epileptic encephalomyopathy.'** The case of Charlie Gard, an infant who was hospitalized in England due to a mitochondrial DNA depletion syndrome that led to an epileptic encephalomyopathy, was highly publicized. Though Charlie's parents lobbied for him to receive experimental nucleoside replacement therapy as a desperate effort to save him, this request was denied, and after a lengthy legal battle, he died in late July 2017. **Full text:** https://goo.gl/NL7eGy

  N.B. Additional articles on the Charlie Gard case noted in the 7 May 2018 issue of Media Watch (#562, p.15).

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 p.14.

Hospice aides: The eyes and ears of end-of-life care

MEDSCAPE | Online – 7 May 2018 – Nursing assistants and aides are among the unlicensed healthcare personnel who comprise a significant component of the healthcare workforce [in the U.S.]. In hospice care, these aides deliver what many patients and families would consider the most vital and valuable aspects of end-of-life care. Aides provide bathing and other personal care essential to patient comfort. They also offer psychosocial and spiritual support through their intimate relationships, presence, and listening. It is not uncommon for the hospice aide to provide the interdisciplinary team with the most critical perspectives on the patient's fears, family dynamics, unresolved conflicts, or spiritual distress. Thus, the first half of the title of a recent article, 'We're the eyes and the ears…' is very fitting. Unfortunately, the second half of the title, '…but we don't have a voice,' is also true.[1] This study provides a unique perspective from these caregivers... After participating in focus group discussions, aides were directly observed providing in-home hospice care. The researchers who shadowed the aides in the home setting took detailed field notes on how the aides communicated and interacted with family caregivers and other patient care providers. This resulted in very rich descriptions of the experiences of the aides and the many unrealized opportunities to include them in the care of seriously ill and dying patients and their families. **Full text:** https://goo.gl/jNjUDw

1. 'We're the eyes and the ears, but we don't have a voice: Perspectives of hospice aides,' *Journal of Hospice & Palliative Nursing*, 2018;20(1):47-54. [Noted in the 8 January 2018 issue of Media Watch (#545, p.12)] **Abstract:** https://goo.gl/iQmRxC

Adaptation, acceptance and adaptive preferences in health and capability well-being measurement amongst those approaching end of life

THE PATIENT | Online – 9 May 2018 – Adaptive preferences occur when people subconsciously alter their views to account for the possibilities available to them. Adaptive preferences may be problematic where these views are used in resource allocation decisions because they may lead to underestimation of the true benefits of providing services. This research explored the nature and extent of both adaptation (changing to better suit the context) and adaptive preferences (altering preferences in response to restricted options) in individuals approaching the end of life (EoL). The authors conducted "think aloud" interviews with 33 hospice patients, 22 close persons and 17 health professionals. Participants spoke clearly about how patients had adapted their lives in response to symptoms associated with their terminal condition. It was often seen as a positive choice to accept their state and adapt in this way but, at the same time, most patients were fully aware of the health and capability losses that they had faced. Self-assessments of health and capability generally appeared to reflect the pre-adaptation state, although there were exceptions. **Abstract (inc. list of references):** https://goo.gl/wfX8Xa

Palliative care volunteerism across the healthcare system: A survey study

PALLIATIVE MEDICINE | Online – 8 May 2018 – Volunteers fulfil several roles in supporting terminally ill people and their relatives and can positively influence quality of care. Healthcare in many countries faces resource constraints and some governments now expect communities to provide an increasing proportion of palliative care (PC). However, systematic insights into volunteer presence, tasks and training and organisational challenges for volunteerism are lacking. Responses were obtained for 254 (79%) organisations [across the Flemish healthcare system]; 80% have volunteers providing direct patient care. Psychosocial, signalling and existential care tasks were the most prevalent volunteer tasks. The most cited organisational barriers were finding suitable (84%) and new (80%) volunteers; 33% of organisations offered obligatory training (75% dedicated PC, 12% nursing homes). Differences in volunteer use were associated with training needs and prevalence of organisational barriers. Results suggest potential for larger volunteer contingents. **Full text:** https://goo.gl/P4AMkv

N.B. Additional articles on the role of volunteers in hospice and palliative care noted in the 26 March 2018 issue of Media Watch (#556, p.10).

The development of specialized palliative care in the community: A qualitative study of the evolution of 15 teams

PALLIATIVE MEDICINE | Online – 8 May 2018 – Community-based specialized palliative care (PC) has been shown to improve symptom management and quality of life, and reduce healthcare costs compared to usual homecare. Existing validated frameworks on community-based PC teams, however, describe theoretical phases and antecedent factors, but lack operational and practical details required for team development. The authors synthesize the experiences from fifteen diverse specialized, community-based PC teams. They detail the characterizing features, activities, milestones, and challenges unique to each of four stages of team evolution evident: inception, start-up, growth, and mature. The authors describe output and outcome measures that are appropriate to each stage. Defining common stages in the evolution of community-based PC teams can inform the development of new teams. Using stage-appropriate milestones and measures can gauge progress and set realistic expectations for team growth. **Full text:** https://goo.gl/Kkvqpg

Wiisokotaatiwin: Development and evaluation of a community-based palliative care program in Naotkamegwanning First Nation

RURAL & REMOTE HEALTH | Online – 28 April 2018 – This article describes an innovative, community-based palliative care (PC) program (Wiisokotaatiwin) developed in rural Naotkamegwanning (Northwestern Ontario, Canada) The Wiisokotaatiwin Program allowed community members to receive their PC at home, improved client experience and enhanced service integration. This article provides a First Nations specific model for a PC program that overcomes jurisdictional issues at the local level, and a methodology for developing and evaluating community-based PC programs in rural First Nations communities. The authors demonstrate how local, federal and provincial healthcare providers and organizations collaborated to build capacity, fund and deliver community-based PC. The described process of developing the program has applicability in other First Nations (Indigenous) communities and for healthcare decision makers. **Full text:** https://goo.gl/ZGTWrm

Approximately 474,000 Indigenous people...

...live in 617 First Nations communities across Canada; 125 of those communities are located in Ontario, primarily in rural and remote areas. Common rural health challenges, including for palliative care (PC), involve quality and access. The need for culturally relevant PC programs in First Nations communities is urgent because the population is aging with a high burden of chronic and terminal disease. Because local PC is lacking, most First Nations people now leave their culture, family and community to receive care in distant hospitals or long-term care homes. Due to jurisdictional issues, a policy gap exists where neither federal nor provincial governments takes responsibility for funding PC in First Nations communities. Further, no Canadian program models existed for how different levels of government can collaborate to fund and deliver PC in First Nations communities.

Noted in Media Watch 7 May 2018 (#562, p.8):

- *ANNALS OF PALLIATIVE MEDICINE* | Online – Accessed 5 May 2018 – **'Developing palliative care programs in Indigenous communities using participatory action research: A Canadian application of the public health approach to palliative care.'** This research contributes to the international literature on public health and palliative care (PC) in Indigenous communities. It also provides Canadian evidence of the benefits of community capacity development to create culturally appropriate PC programs. The research adds understanding of how Indigenous communities can mobilize to provide PC and illustrates the appropriateness of using the public health approach where end of life is viewed from a social, cultural and community lens. **Full text:** https://goo.gl/ZsemD5

Cont.

Related

- *BMC PALLIATIVE CARE* | Online – 8 May 2018 – **'Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the U.S.: A comprehensive review.'** This review highlights the key features of culturally safe service delivery that have been reported to be working well in the Indigenous palliative care (PC) context. A flexible approach, adaptability to the context and "buy-in" from local communities are reported to be some of the essential features of successful service models to deliver PC services to Indigenous populations and the literature emphasises that a "one size fits all" approach is not appropriate. **Full text:** https://goo.gl/9pDGJW

N.B. For additional articles on palliative care for Indigenous peoples see back issues of Media Report: In Australia, the 10 July 2017 issue (#520, p.13); and, in New Zealand, Canada and the U.S., the 7 May 2018 issue (#562, p.8, p.12)

Does implementation matter if comprehension is lacking? A qualitative investigation into perceptions of advance care planning in people with cancer

SUPPORTIVE CARE IN CANCER | Online – 11 May 2018 – This study highlights that advance care planning (ACP) was not a completely accurate representation of patient wishes [i.e., among those of study participants]. Data collection comprised interviews and an examination of participants' existing ACP documentation. Participants included those who had any diagnosis of cancer with an advance care plan recorded: Refusal of Treatment Certificate, Statement of Choices, and/or Enduring Power of Attorney (Medical Treatment) at one cancer treatment centre. Three themes were evident from the data collected: 1) Incomplete ACP understanding and confidence; 2) Limited congruence for attitude and documentation; and, 3) ACP can enable peace of mind. Complete ACP understanding was unusual; most participants demonstrated partial comprehension of their own advance care plan, and some indicated very limited understanding. **Abstract (inc. list of references):** https://goo.gl/FB5WdZ

Muslim physicians and palliative care: Attitudes towards the use of palliative sedation

SUPPORTIVE CARE IN CANCER | Online – 8 May 2018 – Muslim norms concerning palliative sedation (PS) can differ from secular and non-Muslim perceptions. Muslim physicians working in a Western environment are expected to administer PS when medically indicated. Therefore, they can experience tension between religious and medical norms. Two main themes were identified [in this study]: professional self-concept and attitudes towards death and dying. Participants emphasized their professional responsibility when making treatment decisions, even when these contravened the prevalent views of Islamic scholars. Almost all of them expressed the moral obligation to fight their patients' pain in the final stage of life. Absence of acceleration of death was considered a prerequisite for using PS by most participants. **Full text:** https://goo.gl/sWtzyG

N.B. Additional articles on the Islamic perspective on end-of-life and end-of-life care noted in the 5 & 12 February 2018 issues of Media Watch (#549, p.8 and #550, p.14, respectively).

Clinicians' perceptions of medication errors with opioids in cancer and palliative care services: A priority setting report

SUPPORTIVE CARE IN CANCER | Online – 4 May 2018 – The authors report the findings of a priority setting process, undertaken with cancer and palliative care (PC) clinicians, to better understand the characteristics of medication errors with opioids within their services. Participants representing six public hospitals in one Australian state took part in a series of workshops and, drawing on actual incidents occurring in their services, sought to identify where in the opioid medication process errors were most frequently occurring. Opioid error types and perceived contributing factors were explored, and strategies to reduce/prevent opioid errors were proposed. The priority setting process provided valuable insights into the types of opioid errors that occur in cancer and PC services and the complexity of addressing opioid errors from the clinician's perspective. **Abstract (inc. list of references):** https://goo.gl/JDtm9A

N.B. Additional articles on medication errors in palliative care noted in the 26 February 2018 issue of Media Watch (#552, p.15).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN JOURNAL OF PUBLIC HEALTH* | Online – 7 May 2018 – **'Canadian and Dutch doctors' roles in assistance in dying.'** According to the Canadian law legalizing physicians to provide medical assistance in dying (MAiD) under certain circumstances, the patients alone determine if their suffering cannot be relieved under conditions "that they consider acceptable." This contrasts with the laws on MAiD in The Netherlands, which require that physicians only grant access to MAiD if they concur with the patient that there are no other potential means of alleviating the suffering. In The Netherlands, when a doctor believes that other means to reduce the suffering exist, they must be tried before having access to MAiD. This criterion is often applied and is considered an essential precaution to ensure that lives are not ended prematurely when other viable interventions exist. The Canadian emphasis on the patient's right to decide whether to try potential alternatives a physician may suggest, such as palliative care, instead of dying by MAiD, gives patients the liberty to make informed decisions, even when they may not seem to be in their best interest. This contrasts with the belief in The Netherlands that the state has an obligation to protect citizens from making decisions that are not in their best interest, such as choosing to die when the "intolerable suffering" can be diminished sufficiently for the person to abandon the desire to end the suffering by dying. The Canadian parliament, when they consider expanding access to MAiD, should incorporate the Dutch due care safeguards to ensure that death is not the solution when other ways of reducing suffering exist. **Abstract (inc. list of references):** https://goo.gl/zyHZD1

- *POLITICS AND THE LIFE SCIENCES*, 2018;37(1):68-77. **'Subduing attitude polarization?: How partisan news may not affect attitude polarization for online publics.'** Researchers have sought to understand the effects of like-minded versus contrary news exposure on attitude polarization, which can be a threat to democracy. The online news environment offers opportunities for exposure to both types of news, albeit unequally. This study tests the effects of exposure to heterogeneous partisan news bundles (both like-minded and contrary news) on attitude polarization. Because media exposure can lead to bias, attitude polarization is tested as a direct and indirect effect via hostile media perceptions. Data are from a between-subjects experimental design about the issue of assisted suicide. Results indicate that even though the effect of the partisan news bundle on hostile media perceptions is significant, both direct and indirect effects on attitude polarization are null. **Abstract (inc. list of references):** https://goo.gl/1J7bkk

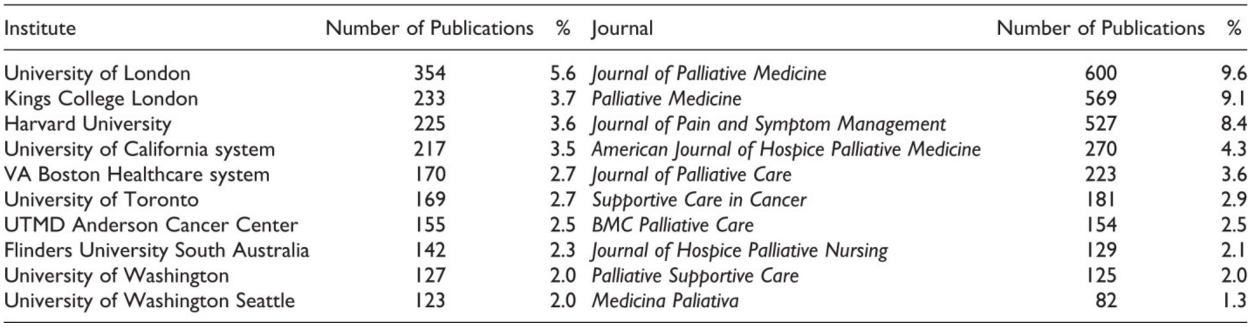
Journal Watch

Bibliometric analysis of palliative care-related publication trends during 2001 to 2016

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE | Online – 8 May 2018 – This study has represented a number of characteristics of palliative care (PC) research: 1) The number of PC publications has gradually increased during the period of 16 years; 2) U.S. authors dominated this field (Australia had gained the highest productive ability in PC research); 3) The annual impact factor (IF) rose progressively with time and increased from 1.13 to 2.24 from 2003 to 2016; and, 4) The number of publications were correlated with Gross Domestic Product. Most publications originated from developed countries. The U.S. continues to dominate the field and has a great deal of international influence on scientific research. However, the authors noticed a remarkable growth rate in East Asia during the past 16 years, which possibly is related to the increasingly valued issue of the population fast-aging and long-term care in this area. Some of these East Asian countries were also ranked among top 20 in the 2015 Quality of Death Index that measured the quality of PC in 80 countries.[1] The *Journal of Palliative Medicine* and *Palliative Medicine* have published the greatest number of publications-related PC, which is logical because it is specific for the PC. In addition, it is notable that about 20% articles without citations are found in this studies. The authors also found that the majority of the top 10 institutes publishing PC-related articles were universities. Most had affiliated hospitals or medical center providing supportive environments for medical education and research. **Full text:** https://goo.gl/SukS2z

Cont.

Institutes and Journals Publishing Palliative Care-related articles



Institute	Number of Publications	%	Journal	Number of Publications	%
University of London	354	5.6	*Journal of Palliative Medicine*	600	9.6
Kings College London	233	3.7	*Palliative Medicine*	569	9.1
Harvard University	225	3.6	*Journal of Pain and Symptom Management*	527	8.4
University of California system	217	3.5	*American Journal of Hospice Palliative Medicine*	270	4.3
VA Boston Healthcare system	170	2.7	*Journal of Palliative Care*	223	3.6
University of Toronto	169	2.7	*Supportive Care in Cancer*	181	2.9
UTMD Anderson Cancer Center	155	2.5	*BMC Palliative Care*	154	2.5
Flinders University South Australia	142	2.3	*Journal of Hospice Palliative Nursing*	129	2.1
University of Washington	127	2.0	*Palliative Supportive Care*	125	2.0
University of Washington Seattle	123	2.0	*Medicina Paliativa*	82	1.3

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit (London, U.K.), October 2015. (See 'Case study: China – growing awareness,' p.20-21.) Commissioned by the Lien Foundation of Singapore. [Noted in the 12 October 2015 issue of Media Watch (#431, p.6)] https://goo.gl/zXrniA

Worth Repeating

Lessons about dying and death from the classroom of the bedside

ANNALS OF BEHAVIORAL SCIENCE & MEDICAL EDUCATION, 2015;21(1):3-5. Medical education about care of the dying is not always conducted systematically at the patient's bedside. Unfortunately, neither life experience nor lecture style pedagogy is an adequate substitute for teaching medical students and residents about caring for the terminally ill. Obstacles to involving trainees in the bedside care of the dying include a general cultural avoidance of death, discomfort among faculty mentors when dealing with death, and uneven application of established rubrics for conveying the art of bedside care of the dying. Valuable lessons about dying and death can be taught if medical educators will model for trainees the delivery of sensitive, compassionate care of the dying and involve them in active learning by convening the "classroom of the bedside." **Abstract (inc. list of references):** https://goo.gl/bmJkvy

Noted in Media Watch 2 June 2014 (#360, pp.8-9):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2014;311(19):1971-1972. **'Bedside teach-ing rounds reconsidered.'** Barriers to bedside teaching are insufficient time to teach, dependence of diagnosis on technology, obstacles created by infection control, and distractions from clinical respon-sibilities at distant computer stations. Many teachers find bedside teaching inherently difficult: **First page view:** https://goo.gl/KwFMJ7

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.

Links to Sources

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

Something Missed or Overlooked?

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

Search Back Issues of Media Watch @ http://goo.gl/frPgZ5

Media Watch Archives

- 2017, Jan - Dec
- 2016, Jan - Dec
- 2015, Jan - Dec
- 2014, July - December
- 2014, January - June
- 2013, July - December
- 2013, January - June
- 2012, July - December
- 2012, January - June
- 2011, July - December
- 2011, January - June
- Current

Media Watch: Access on Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/T2tCWF

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://goo.gl/frPgZ5

PALLIATIVE CARE NETWORK-e: http://goo.gl/8JyLmE

PALLIMED: http://goo.gl/7mrgMQ

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

Asia

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

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

Cont.

Australia

PALLIATIVE CARE WESTERN AUSTRALIA: https://goo.gl/fCzNTL

[Scroll down to 'International Websites']

Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: https://goo.gl/qw5ti8

[Click on 'National Resources,' scroll down to 'Palliative Care Network Community']

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

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

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

[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/lOSNC7

ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYC

[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

SASKATCHEWAN | Saskatchewan Medical Association: https://goo.gl/5cftPV

[Scroll down to 'Palliative Care Network Community']

Europe

EUROPEAN JOURNAL OF PALLIATIVE CARE: https://goo.gl/KjrR6F

[March/April 2018 issue (Scroll down to 'The homeless: A vulnerable population with poor access to palliative care.']

HUNGARY | Magyar Hospice Alapítvány: https://goo.gl/3jnH7K

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

South America

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

Palliative Care Network

Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8I

Barry R. Ashpole
Guelph, Ontario CANADA

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