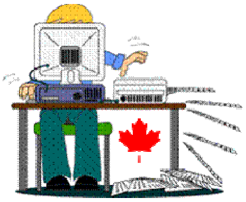
Media Watch... *is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in* ***hospice*** *and* ***palliative care****, and in the quality of* ***end-of-life care*** *in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.*

10 December 2018 Edition | Issue #593



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Compiled & Annotated by Barry R. Ashpole

'The Unfinished Business in Bereavement Scale: Development and psychometric evaluation' (p.10) in *Death Studies.*

Canada

Framework on Palliative Care in Canada

HEALTH CANADA | Online – 4 December 2018 – In late 2017, the Framework on Palliative Care in Canada Act was passed by Parliament with all-party support. During the spring and summer of 2018, Health Canada consulted with provincial and territorial governments, other federal departments, and national stakeholders, as well as people living with life-limiting illnesses, caregivers and Canadians. The findings from that consultation, as well as the requirements outlined in the Act, provided the foundation for the 'Framework on Palliative Care in Canada.' The Framework sets out the collective vision for palliative care (PC) in Canada: that all Canadians with life-limiting illnesses live well until the end of life. Key to this vision is a set of guiding principles, developed in collaboration with participants of the consultative process. These principles help reflect the Canadian context and are considered fundamental to the provision of high-quality PC in Canada. The Framework provides a blueprint to help shape planning, decision making, and organizational change within the current context and identifies existing efforts and best practices, and sets out goals and a range of priorities for short, medium and long term action to improve each of the four priority areas: 1) PC education and training for health care providers and caregivers; 2) Measures to support PC providers; 3) Research and the collection of data on PC; and, 4) Measures to facilitate equitable access to PC across Canada, with a closer look at underserviced populations. **Download/view at:** https://goo.gl/K7DLVm

Specialist Publications

'Early initiation of palliative care is associated with reduced late-life acute-hospital use: A population-based retrospective cohort study' (p.15), in *Palliative Medicine*.

N.B. Selected articles on the development of a national PC strategy in Canada noted in 18 December 2017 and 1 January 2018 issues of Media Watch (#543, pp.1-2 and #544, pp.18-19, respectively).

Cont.

Noted in Media Watch 24 September 2018 (#582, p.1):

- *THE GLOBE & MAIL* | Online – 19 September 2018 – **'Almost all Canadians would benefit from palliative care. Only one in seven can actually access it at end-of-life.'** An estimated 89% of Canadians could benefit from palliative care (PC) in the last year of life. But only 15% are actually getting it. That's a pretty damning commentary on the state of end-of-life care in this country, and it only tells part of the story. The new data reveals that even those who get PC tend to get it late, and that far too many dying patients are shuffled around mercilessly between home, hospitals and nursing homes in their final days.[1] https://goo.gl/mQDk6q

    1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, September 2018. **Download/view (scroll down to foot of page and 'Related Links') at:** https://goo.gl/qE2smV

- *INTERNATIONAL JOURNAL OF POPULATION DATA SCIENCE* | Online – 6 September 2018 – **'Access to palliative care in Canada.'** The authors present the findings of a study on whether Canadian decedents had access to palliative care (PC) in the last year of life. Data from physician billings, drug claims, home care, long-term care and acute care were linked to identify decedents and PC service use. These data were also used to examine how PC may affect, or be affected by other interactions with the health system, including inpatient alternate level care days, admissions from long-term care, emergency department visits and stays in intensive care units. **Abstract:** https://goo.gl/BoR7As

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | CTV News (Montreal) – 5 December 2018 – **'McGill University Health Centre study seeks to ensure patients have enough information on medical aid in dying.'** A new study on medical aid in dying in Quebec is sparking conversation about whether patients are receiving enough information in palliative care (PC) consultations.[1] The McGill University Health Centre (MUHC) study looked into 80 patient files of people who requested and received medical aid in dying (MAiD), and it found that a good portion of them received palliative consultations as little as seven days or fewer before requesting MAiD. People in PC are typically consulted about the full scope of their end-of-life care options. It is important to note that these patients were very ill and in many cases in severe pain; researchers stress that this is not a condemnation of MAiD, but a starting point for further discussion on how the process unfolds. Researchers discovered that in some cases, people who requested MAiD continued to receive life-prolonging care for a time. While it seems like a paradox on the surface, there could be reasonable explanations for those cases, explained Lori Seller, ethics advisor for the Centre for Applied Ethics at the MUHC. https://goo.gl/dcjXG3

    1. 'Situating requests for medical aid in dying within the broader context of end-of-life care: Ethical considerations,' *Journal of Medical Ethics*, published online 21 November 2018. [Noted in 26 November 2018 issue of Media Watch (#591, p.20)] **Abstract:** https://goo.gl/1SJstG

    N.B. MAiD = medical *assistance* in dying.

- ALBERTA | *The Edmonton Journal* – 3 December 2018 – **'Covenant Health updates medical aid in dying policy after patients have consultations on the street.'** Patients considering assisted death are now allowed to have eligibility assessments and sign documents in Catholic hospitals and care homes, says a revised Covenant Health policy. In the wake of documents showing Covenant staff skirted the organization's existing policy, and tales of patients forced onto the sidewalk or a bus shelter to ask for help to die, the Catholic health-care organization published its revised approach to the thorny issue... The organization, which runs 17 Alberta health facilities … still prohibits assisted deaths from taking place in its facilities. Covenant staff will not conduct any assessments to see if a patient is eligible for medical aid in dying – the organization must respect health-care workers' rights to conscientiously object to hastening a person's death... The new policy does clarify who does what when a patient inquires about assisted death. Doctors and nurse practitioners can provide information about medical aid in dying, but if the patient wants to follow through, they'll have to contact Alberta Health Services, or ask a Covenant employee to do that for them. https://goo.gl/dMCfrh

    N.B. Additional articles, reports, etc., on faith-based hospitals *vis-à-vis* medical assistance in dying noted in 29 October and 12 November 2018 issues of Media Watch (#587, p.2 and #589, p.2, respectively). **Download/view Covenant Health's revised policy on medical assistance in dying at:** https://goo.gl/VGkngb

U.S.A.

Life-sustaining treatment decisions for unbefriended nursing home residents: Application of a clinical ethics algorithm

STATE OF NEW YORK | Health Law Journal (New York State Bar Association), 2018;23(2): 80-89. Due to fear of running afoul of regulations, clinicians are reluctant to make decisions to withhold or withdraw life-sustaining treatment (LST) when patients cannot express treatment preferences and also lack available surrogate decision-makers. For these unbefriended patients, the resulting failure to make LST decisions can lead to medically inappropriate treatments of great burden and little benefit. To assist clinicians with making LST decisions, New York City's public hospitals and nursing homes developed an algorithm for the unbefriended in 2016, which is intended to serve as a quality improvement aid, delineating a procedural method that provides a framework for clinical ethics consultations and is compliant with applicable laws and regulations, including New York's Family Health Care Decisions Act. Based upon the outcome results achieved at the Coler Rehabilitation & Nursing Care Center and a satisfaction survey, the algorithm has proven to be a very useful measure to help address the end-of-life (EoL) care needs of this highly vulnerable population in an ethical and compassionate manner, with built-in safeguards that greatly minimize the likelihood that arbitrary decisions are made. It has de-emphasized solo decision making by the attending physician and empowered the interdisciplinary care team with the lead of the ethics consultant to fully address the goals-of-care for the vulnerable unbefriended adult. The algorithm has provided guidance in addressing burdensome life-sustaining treatment with limited clinical benefit to individuals at the EOL. The authors attribute the success of the algorithm to a transparent interdisciplinary panel approach, allowing each care team member to participate in decision-making for the patient's best interest while adhering to evidence-based best practices. **Full text:** https://goo.gl/quy1bw

Specialist Publications

'Calculating the incidence rate of sibling bereavement among children and adolescents across the U.S.: A proposed method' (p.9), in *Death Studies*.

'Effect of living wills on end-of-life: A systematic review' (p.12), in *Journal of American Geriatric Society*.

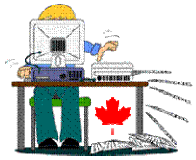
'Quality of end-of-life care and its association with nurse practice environments in U.S. hospitals' (p.12), in *Journal of the American Geriatric Society*.

'Ten-year trends of palliative care utilization associated with multiple sclerosis patients in the U.S. from 2005 to 2014' (p.13) in *Journal of Clinical Neuroscience*.

'Racial and ethnic differences in end-of-life care in the U.S.: Evidence from the Health & Retirement Study' (p.16), in *SSM – Population Health*.

'Physician-assisted suicide/physician-assisted death: The rise of lifeboat ethics' (p.17), in *Journal of American Physicians & Surgeons*.

N.B. Selected articles on decision-making for "unbefriended" or "unrepresented" patients noted in 18 September 2017 issue of Media Watch (#530, p.14).



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

LGBT seniors grapple with end-of-life issues

CALIFORNIA | *The Bay Area Reporter* (San Francisco) – 5 December 2018 – Confronting the end of one's life isn't easy for the majority of seniors, whether LGBT or straight. Most have not declared an executor for their estate, let alone discussed with their physician what sort of care they want in their dying days. There are an estimated 2.7 million Americans who are LGBT and 50 years of age or older. Of that age group, 1.1 million are 65 and older. By 2060 LGBT elders in the U.S. are expected to number more than 5 million. This generation of LGBT seniors differs from its heterosexual counterpart in significant ways, according to aging experts. Most of the LGBT seniors experienced discrimination not only in their day-to-day lives but also in medical settings due to their sexual orientation or gender identity. LGBT seniors are oftentimes no longer in touch with their birth families, having been ostracized after they came out of the closet. Many don't have a partner, spouse, or children of their own to rely on as they age. In the case of many older gay men, they lost their families of choice, whether it was their friends, partners, or spouses, to the AIDS epidemic. Thus, they are more likely to be aging alone. And if they are living with HIV, they are largely unprepared for their retirement years having believed they would have died by now. https://goo.gl/uC8Kum

Specialist Publications

'Adding silver to the rainbow: Palliative and end-of-life care for the geriatric LGBTQ patient' (p.14), in *Journal of Palliative Medicine*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *RASMUSSEN REPORTS* | Online – 5 December 2018 – **'Americans still support voluntary euthanasia.'** A new national telephone and online survey finds that 52% of American adults favor a law allowing voluntary euthanasia in the state where they live. Thirty-two percent are opposed to such a law, but 16% remain undecided. The survey of 1,000 American adults was conducted on 2-3 December 2018. https://goo.gl/bzCStp

International

Long wait for home care package increases risk of death, study finds

AUSTRALIA | *Community Care Review* (Glebe, New South Wales) – 6 December 2018 – The study looked at almost 180,000 older people who got a home care package (HPC) between 2003-2013.[1] Of those, 74% got a package within 6 months and 25% after six months. A third received a package within a month. Those who waited longer were more likely to be dead or in permanent care after two years. The study, led by Professor Renuka Visvanathan of the University of Adelaide … found that people who waited more than six months for a HPC had an almost 20% higher risk of dying compared to people who got a HCP within one month. The risk of dying after moving into residential care two years after getting a HCP was also 10% higher for people who had waited longer than six months. https://goo.gl/G283YN

Specialist Publications

'Who are the main medical care providers of European nursing home residents? An European Geriatric Medicine Society survey' (p.10), in *European Geriatric Medicine*.

'"We are all in this together": Building capacity for a community-centred approach to caring, dying and grieving in Australia' (p.11), in *European Journal for Person Centred Healthcare*.

'Palliative care in universal health coverage: What about humanitarian emergency assistance?' (p.11), in *International Journal of Public Health*.

Cont.

1. ‘Prolonged wait time prior to entry to home care packages increases the risk of mortality and transition to permanent residential aged care services…,’ *Journal of Nutrition, Health & Aging*, published online 4 December 2018. **Full text:** https://goo.gl/TgqYNU

Shocking data reveals that someone in their last year of life is rushed to hospital every 20 seconds

U.K. (England, Scotland & Wales) | Marie Curie (London) – 5 December 2018 – Data analysed by the terminal illness charity reveals that of all the emergency hospital admissions in Britain approximately one in four is for someone in their last year of life. Data from the National Health Service (NHS) in England, Scotland & Wales paints a grim picture for patients with a terminal diagnosis who can expect to spend, on average, up to three weeks of precious life stuck on a hospital ward. How often patients are taken to hospital and how long they spend there depends on the illness a person has and where they live. For example, people with dementia in Wales spent, on average, one month of their last year of life in hospital – far higher than in England and Scotland. Lung disease patients in England were taken to hospital twice as often as people in Scotland with the same condition. Cancer patients in Scotland, however, will spend longer in hospital than the national average. Data also shows that cancer patients have more emergency admissions in their last year of life than those with a non-cancer diagnosis, however, non-cancer patients will experience longer stays in hospital with each visit. The charity says that more innovative models of care in hospitals, along with better provision of high quality care in the community, can help get people home from hospital quicker and keep them safe at home. In doing this someone will only get rushed to hospital when they absolutely need to be, resulting in a better quality of life and a much more effective use of already stretched NHS resources. https://goo.gl/NqoKrj

Related

- U.K. (Wales) | Wales 247 (Cardiff) – 5 December 2018 – **‘Dementia patients “spending average of a month in hospital in last year of life.”’** People living with dementia are spending an average of a month in hospital in Wales in their last year of life following emergency admission… Data collected by Marie Curie revealed there were over 51,000 emergency admissions for people with any terminal condition in the last year of their life in Wales in 2016 – with further analysis revealing differences among patients with cancer or non-cancer diagnosis, and stark differences in particular for dementia patients. https://goo.gl/M4wM7F

Lost retirement: The impact on older people of caring for someone with a terminal illness

U.K. (Northern Ireland) | Carers NI (Belfast) – 4 December 2018 – A new report from Marie Curie and Carers NI shows the impact that caring for someone with a terminal illness has on older people’s health and wellbeing, leaving many at “breaking point.” There are over 32,000 local carers aged 65 and over, and this is the fastest growing carer age group in Northern Ireland. These older carers provide thousands of hours of unpaid care every day – potentially saving the health service hundreds of millions of pounds a year. Local demographic trends mean that even if the proportion of people aged 65+ who are carers merely remained static, there could still be nearly 63,000 older people performing caring roles by 2041 – almost double the current number. Older carers often have to manage the physical demands of caring on their own health at the same time as the impact of ageing. Neglecting their own health needs and struggling to eat properly or get a good night’s sleep because of the demands of caring can have a significant impact on their physical health. Caring for someone with a terminal illness can also impose an enormous mental and emotional strain; many older carers experience feelings of fear, anxiety, uncertainty, loneliness and depression. Caring for someone with a terminal illness can have a significant financial impact for older people. **Download/view at:** https://goo.gl/mKhafn

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Doctors call for death ed in schools

AUSTRALIA (Queensland) | *EducationHQ* (Brunswick West, Victoria) – 3 December 2018 – The Australian Medical Association of Queensland (AMAQ) is calling for more education around death and dying, and they want the discussion to start in schools. AMAQ has proposed an addition to the Australian curriculum to help young people cope with loss and demystify the end of life (EoL). English, maths and the odd unit on death? Dr Richard Kidd says it shouldn't sound as outlandish as it might. The chair of general practice says his members have seen too many tragic incidences where young people were left to contend with the consequences of a death with little in the way of preparation. The association says the need for better education around the issue is underscored by the country's rapidly ageing population. According to the Australian Bureau of Statistics, the number of people over 65 has increased from 12% to 15.3% in the decade from 1996, with that trend set to increase as the baby boomer generation ages. This will inevitably put the onus on younger generations to make arrangements for EoL care such as advanced care plans... https://goo.gl/fa3XiW

Selected articles on including the topic of dying and death in the school curriculum

PASTORAL CARE IN EDUCATION | Online – 28 March 2017 – **'Making death, compassion and partnership "part of life" in school communities.'** [Noted in 10 April 2017 issue of Media Watch (#507, p.16)] **Abstract (w. link to references):** https://goo.gl/V4H7NR

U.S. (California) | NPR News – 25 February 2017 – **'Doctor takes death education to high school classrooms.'** [Noted in 27 February 2017 issue of Media Watch (#501, p.1) https://goo.gl/496EbZ

U.S. (Hawaii) | KITV 4 News – 10 February 2015 – **'Iolani School offers hospice course to students.'** [Noted in 23 February 2015 issue of Media Watch (#398, p.4)] https://goo.gl/9n6Khe

U.S. (Minnesota) | *International Falls Daily Journal* – 29 October 2011 – **'Students participate in end-of-life simulation.'** [Noted in 31 October 2011 issue of Media Watch (#225, p.3)] http://goo.gl/cr7w5K

Scottish Partnership for Palliative Care position paper on the impacts of Brexit on palliative and end-of-life care

U.K. (Scotland) | Scottish Partnership for Palliative Care (SPPC) – 2 December 2019 – The paper starts by acknowledging the uncertainties currently surrounding Brexit and describes its approach to conducting analysis in spite of this uncertainty. After providing some background on SPPC and palliative care (PC) in Scotland, the paper describes current "non-Brexit" challenges in PC. The impact of Brexit on the key domains of workforce, scientific research, medicine supply and funding are then considered. The paper contains the findings of a recent SPPC survey designed to capture the views of people who are involved in a professional capacity in providing care for people approaching the end of life (EoL) in Scotland. Based on its assessment of available evidence and information the paper concludes that Brexit will have a negative impact on palliative and EoL care. In all likelihood Brexit will significantly damage the care which people receive towards the EoL. SPPC exists to improve palliative and EoL care in Scotland. It is not a role of SPPC to assess or to comment on the wider merits and demerits of Brexit. However, in terms of what is best for the care of people approaching the end of their lives in Scotland, SPPC concludes that it would be better to avoid Brexit. **Download/view at:** https://goo.gl/a81sgb

Noted in Media Watch 30 October 2017 (#536, p.7):

- U.K. (Scotland) | Scottish Partnership for Palliative Care – 26 October 2017 – **'Palliative care sector raises concerns over Brexit.'** Brexit could have a disruptive impact on care of the dying in Scotland: 1) Uncertainty over Brexit has already reduced the numbers of European Union (EU) nurses registering to practice in the U.K.; 2) 4% of nurses and midwives in National Health Service Scotland are non-British EU nationals, as are 1,400 doctors; and, 3) 6% of the care home workforce are non-British EU nationals. The Partnership expresses concern over the future of EU research funding and cross-border collaboration into the improvement of end-of-life care. Clinical medicine and biosciences research received well over £200 million in EU research funding in 2014-2015. https://goo.gl/pV9hrz

Specialist Publications

Managing implantable cardioverter-defibrillators at end of life: Practical challenges and care considerations

AMERICAN JOURNAL OF THE MEDICAL SCIENCES | Online – 29 November 2018 – Cardiopulmonary arrest serves as the final common pathway of natural death, and the appropriate management of an implantable cardioverter-defibrillators (ICD) near the end of life (EoL) is crucial to ensure that a patient's death is not marked by further suffering due to ICD shocks. The tenets of palliative care at the EoL include addressing any medical intervention that may preclude dying with dignity; thus management of ICDs during this phase is necessary. Internists are at the forefront of discussions about EoL care, and are likely to find discussions about ICD care at the EoL particularly challenging. This review addresses issues pertaining to ICDs near the end of a patient's life and their potential impact on dying patients and their families. **Abstract:** https://goo.gl/ga8N2S

Noted in Media Watch 23 April 2018 (#560, p.13):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2018;20(1):63-71. **'Deactivation of implantable cardioverter-defibrillators in heart failure: A systematic review.'** Studies reported low occurrence of deactivation discussions, lack of knowledge regarding implantable cardioverter-defibrillator deactivation among most patients, and provider's perception of being unqualified to initiate discussion and perform deactivation of implantable cardioverter-defibrillator. **Abstract:** https://goo.gl/wwbfmx

N.B. Additional articles on managing implantable ICD at the EoL noted in 23 January 2017 issue of Media Watch (#496, p.8).

What enables good end-of-life care for people with dementia? A multi-method qualitative study with key stakeholders

BMC GERIATRICS | Online – 4 December 2018 – This unique study provides a rich evidence-base which confirms the relevance of much of the content of existing end-of-life (EoL) frameworks to dementia. It also highlights the different priorities which characterise different stakeholder groups, drawing attention to the need to tailor interventions to individual people with dementia and their carers. The findings indicate that a wide range of areas need to be addressed by initiatives to improve EoL care in dementia. In addition to addressing all seven of the areas suggested by the authors' research (rather than focusing on specific aspects in isolation), any intervention needs to focus both on optimising care delivery to individual people with dementia as well as their families and on developing systems in terms of policies and procedures to support EoL care. **Full text (w. link to open peer review reports):** https://goo.gl/TbjxVi

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 December 2018 – **'What does death preparedness mean for family caregivers of persons with dementia?'** Most importantly attributes include: 1) Knowing and recognizing the symptoms of decline in dementia and what dying looks like; 2) Understanding emotions and grief responses; 3) Accessing and appraising supports needed to manage and care for dying; 4) Organizing affairs and completing tasks in advance; 5) Accepting that losses are inevitable and imminent; 6) Reflecting on caregiving and finding meaning, "a silver-lining"; and, 7) Closing, reconciling, and renewing relationship bonds and completing the family member's life. **Abstract:** https://goo.gl/Cq8kcx

N.B. Selected articles on EoL care for people living with Alzheimer's and other forms of dementia noted in 26 November 2018 issue of Media Watch (#591, p.17).

The liminal space palliative care volunteers occupy and their roles within it: A qualitative study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 7 December 2018 – Volunteers have an important place in palliative care (PC), positively influencing quality of care for seriously ill people and those close to them and providing a link to the community. However, it is not well understood where volunteers fit into PC provision or how to support them adequately. The authors describe volunteer roles across care settings through the perspective of those closely involved in the care of terminally ill people. Seventy-nine people participated in the study. Two volunteer roles were identified. The first was "being there" for the dying person. Volunteers represent a more approachable face of care, focused on psychological, social and existential care and building relationships. The second was the "liaison" role. Volunteers occupy a liminal space between the professional and the family domain, through which they notice and communicate patient needs missed by other caregivers. Patient-volunteer matching was a facilitator for role performance; barriers were lack of communication opportunities with professional caregivers and lack of volunteer coordination. **Abstract:** https://goo.gl/X6qiEY

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Noted in Media Watch 5 November 2018 (#588, p.12):

- *PALLIATIVE MEDICINE IN PRACTICE*, 2018;12(3):131-134. **"Being there"** Volunteer hospice teams are part of the nationwide Austrian concept of a 'Graded Hospice & Palliative Care System.' This three-level system was commissioned by the Ministry of Health and developed by the Austrian Federal Institute of Health, a national research and planning institute for health care, in joint cooperation with Hospice Austria in 2004. By the end of 2016, there were 3,528 hospice and palliative care volunteers in Austria. 2,929 volunteers belonged to one of the 162 hospice teams and were involved in direct patient care, 599 volunteers were performing other tasks in their hospice teams or were working within coordinating organizations in their federal state… **Abstract (inc. list of references):** https://goo.gl/3g6W9R

Noted in Media Watch 22 October 2018 (#586, p.10):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 16 October 2018 – **'Volunteer involvement in the organisation of palliative care: A survey study of the healthcare system in Flanders and Dutch-speaking Brussels, Belgium.'** The authors provide an extensive description of the involvement of volunteers who provide direct patient palliative care (PC) across the Flemish healthcare system in Belgium. Degree of involvement was found to be positively associated with volunteer training and performance of practical and psychosocial care tasks. Dedicated PC services displayed a strong degree of volunteer involvement, contrary to generalist PC services, suggesting volunteers have a more important position in dedicated PC services. **Abstract:** https://goo.gl/bo2TAz

Behind the wheel safety in palliative care: A literature review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 6 December 2018 – Driving is a complex activity that requires physical abilities and adequate executive and cognitive functioning. There is concern among specialist palliative care (PC) services about patients continuing to drive despite having progressive incurable illnesses, comorbidities and medications to manage their symptoms. This review highlights the scarcity of studies available for patients who would be known to PC services. For most patient groups, a battery of neuro-cognitive tests combined with a road-test or simulated driving assessment is still considered the best practice in determining driving safety. **Abstract:** https://goo.gl/LnrrMa

The informal curriculum: What do junior doctors learn from a palliative care rotation?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 4 December 2018 – Junior doctors learn from the formal and informal curriculum. In a palliative care rotation, the informal curriculum may be useful in teaching attitudes like empathy and compassion. In this study, three main themes illustrated how the in-

Cont.

formal curriculum influenced the doctors: 1) Reconceptualisation of control: shifting perspectives as they grappled with their envisioned control versus reality while caring for dying patients; 2) Emergence of professionalism: adapting perspectives as they learnt how to bridge theory and reality while developing professionalism; and, 3) Personal growth: forming new perspectives, as doctors reflected on life, death and their calling through a renewed lens. **Abstract:** https://goo.gl/FQbw6N

Palliative care: Needs of advanced breast cancer patients

BREAST CANCER: TARGETS & THERAPY | Online – 3 December 2018 – Advanced breast cancer is characterized by many physical manifestations with the potential to undermine the quality of life (QoL) – most related to the cancer and some to treatments – as well as substantial impact on psychosocial well-being. Patients with advanced breast cancer and their families have complex needs that have to be addressed in order to minimize severe distress and deterioration in the QoL of patients and their family members. This task requires the full engagement of an interdisciplinary approach to palliative care (PC) with strong emphasis on the assessment of needs and anticipated needs, patient expectations, skilled therapeutics, and commitment to continuity of care. The authors address four issues: 1) Organizational and conceptual issues in PC of patients with breast cancer: 2) Common physical symptoms among patients with breast cancer and their management; 3) Common psychological issues among patients with breast cancer; and, 4) Challenging PC problems in breast cancer. **Abstract:** https://goo.gl/QvxYtN

> **N.B.** Selected articles on integrating PC for patients with metastatic breast cancer noted in 15 October 2018 issue of Media Watch (#585, p.2).

Ethical considerations in end-of-life care in the face of clinical futility

CONTINUUM, 2018;24(6):1789-1793. Management of patients with terminal brain disorders can be medically, socially, and ethically complex. Although a growing number of feasible treatment options may exist, there are times when further treatment can no longer meaningfully improve either quality or length of life. Clinicians and patients should discuss goals-of-care while patients are capable of making their own decisions. However, because such discussions can be challenging, they are often postponed. These discussions are then conducted with patients' health care proxies after patients lose the capacity to make their own decisions. Disagreements may arise when a patient's surrogate desires continued aggressive interventions that are either biologically futile (incapable of producing the intended physiologic result) or potentially inappropriate (potentially capable of producing the patient's intended effect but in conflict with the medical team's ethical principles). This article explores best practices in addressing these types of conflicts in the critical care unit, but these concepts also broadly apply to other sites of care. **Abstract:** https://goo.gl/DCdbKr

Calculating the incidence rate of sibling bereavement among children and adolescents across the U.S.: A proposed method

DEATH STUDIES | Online – 4 December 2018 – This study proposes a method for calculating the annual incidence rate of sibling bereavement among U.S. youth using national epidemiological data. The proposed model combines data on family household size with national death statistics to calculate the number of siblings affected by the death of a child annually. From 2012 to 2015, an average of 61,389 children per year experienced the death of a sibling, resulting in an estimate of 0.0832% of children bereaved by the death of a sibling annually. Data indicate a need for greater awareness and dialog concerning the frequency with which children experience the death of a sibling. **Abstract:** https://goo.gl/cqqk89

Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.18.

Terminal lucidity in the teaching hospital setting

DEATH STUDIES | Online – 4 December 2018 – Terminal lucidity (TL) is an unpredictable end-of-life (EoL) experience that has invaluable implications in preparation for death. The authors retrospectively evaluated TL at a university teaching hospital. Of 338 deaths that occurred during the study period (187 in the ICU and 151 in general wards), TL was identified in 6 cases in general wards. Periods of lucidity ranged from several hours to 4 days. After experiencing TL, half of the patients died within a week, and the remainder died within 9 days. More attention should be directed toward understanding TL to improve EoL care in a meaningful way. **Abstract:** https://goo.gl/ZGepYs

N.B. Selected articles on terminal lucidity noted in 30 July 2018 issue of Media Watch (#574, p.3 & p.16).

The Unfinished Business in Bereavement Scale: Development and psychometric evaluation

DEATH STUDIES | Online – 4 December 2018 – Although unresolved issues with the deceased are often targeted in bereavement interventions, understanding of this construct has been hampered by the lack of a psychometrically validated scale to assess it. To address this gap, the Unfinished Business in Bereavement Scale (UBBS) was developed and tested in two samples of bereaved adults... The UBBS was found to be composed of two related factors. Items tapping into "unfulfilled wishes" pertained to unspoken affirmations or missed opportunities with the deceased. These experiences often emerged in loving relationships and only became problematic when accompanied by high levels of distress. In contrast, "unresolved conflict" pertained to unaddressed disputes or indiscretions. It primarily occurred in relationships characterized by anxiety and conflict and conferred risk for prolonged grief reactions even when endorsed at moderate levels. Other findings strongly supported the internal consistency, concurrent validity, and incremental validity of the UBBS. Unfinished business and meaning made of loss together accounted for 50-60% of the variance in prolonged grief symptoms. Implications for clinical practice and future research are discussed. **Abstract:** https://goo.gl/r8Bm96

Related

- *BEHAVIORAL SCIENCES* | Online – 30 November 2018 – **'Community views on "what I want before I die."'** "Before I die" activity encourages people to articulate values in their life more consciously, within the context of understanding that life is finite. It is hoped that this is a useful way for people to become more aware of their mortality and to live their life in a way that is congruent with what they consider to be what really matters the most to them in their lifetime. The potential of this activity for building death awareness and preparedness, and for understanding the impact on personal well-being are important considerations for future research. **Full text:** https://goo.gl/YaQUtU

  N.B. Additional articles on unfinished business in bereavement noted in 21 August 2017 issue of Media Watch (#526, p.13).

Who are the main medical care providers of European nursing home residents? An European Geriatric Medicine Society survey

EUROPEAN GERIATRIC MEDICINE | Online – 30 November 2018 – Nursing home residents are complex, vulnerable and have been historically neglected. The European Geriatric Medicine Society is committed to improving their care, and is currently developing a curriculum of core competencies. Integral to these efforts is identifying the physicians, for whom, education in these competencies needs to be directed. A survey was distributed to European national geriatrics societies, asking members their perceptions of proportions of nursing home medical care delivered by various physician specialties, and the main functions carried out in nursing homes. Responses were received from 22 of 32 national geriatrics societies. The vast majority of care (estimated at 69%), is delivered by GPs, rather than geriatricians or specialist nursing home physicians. Nursing homes have acquired important roles in rehabilitation, respite and palliative care. Education and training to achieve the highest standards of care must be designed for GPs who do not have specialist training. Education and infrastructure must be developed for the evolving roles of nursing homes**. Abstract:** https://goo.gl/qW9pNW

“We are all in this together”: Building capacity for a community-centred approach to caring, dying and grieving in Australia

EUROPEAN JOURNAL FOR PERSON CENTRED HEALTHCARE, 2018;6(4):685-692. “Compassionate communities” is emerging as an international strategy for implementing the public health palliative care approach to end-of-life (EoL). It is a community-centred approach which places people and their naturally occurring networks at the centre of care, death and grief, thus extending the concept of person-centred care to network-centred care. This article describes the first steps in the development of a Compassionate Community in the South West of Western Australia. The aim of this initiative was to create opportunities for conversations around death, dying and loss; identify naturally occurring community connectors and hubs within the community and to foster a compassionate communities model of EoL care for practical and social support. To facilitate a “positive” conversation, a format of a Mini Death Festival was undertaken to engage the broader community and to launch the South West Compassionate Communities Network. Attendees were invited to participate in a brief on-line survey describing their experiences with the event. The death festival enabled the network to identify and develop an extended network of people who see themselves as part of a shared community of interest and who have an understanding of each other’s skills and talents. These individuals are vital assets in furthering the compassionate communities work and potential resources the network can actively partner with to co-design the way forward. **Abstract (w. list of references):** https://goo.gl/7XdsQS

Palliative care in universal health coverage: What about humanitarian emergency assistance?

INTERNATIONAL JOURNAL OF PUBLIC HEALTH | Online – 30 November 2018 – Palliative care (PC) has just started to enter the “culture” of humanitarian organisations. They began to use the term extensively during the Ebola epidemic in West Africa when they were confronted with many patients who could not be cured. While outbreaks will continue to occur, the epidemiology of diseases is shifting towards chronic conditions, even in low-income countries where disasters and armed conflicts are common. Morbidity and mortality caused by non-communicable diseases are about to overtake infectious diseases in adults, and these diseases are usually chronic. The recent *Lancet* Commission report on PC and pain relief in universal health coverage concentrates on injuries and acute conditions.[1] Humanitarian organisations are less experienced in managing chronic conditions with long courses that are steeply increasing the number of patients who need PC. We still know little about how to integrate PC or advanced pain control into medical emergency assistance projects,[2] but the WHO is extending its guidelines on PC to cover emergency assistance,[3] and the new edition of the Sphere Handbook, a collection of recommendations and standards for humanitarian assistance, contains a chapter on PC.[4] **Full text:** https://goo.gl/js4hHv

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 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** https://goo.gl/i7r9M1

2. ‘What do humanitarian emergency organizations do about palliative care? A systematic review,’ *Medicine, Conflict & Survival*, published online 4 December 2017. [Noted in 4 December 2017 issue of Media Watch (#541, p.13)] **Abstract:** https://goo.gl/7dahXr

3. ‘Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises,’ World Health Organization, September 2018. [Noted in 1 October 2018 issue of Media Watch (#583, p.6). **Download/view at:** https://goo.gl/tdnWUB

4. ‘The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response,’ 2018 Edition, Sphere Association, 2018. [Section on palliative care begins on p.345] **Download/view at:** https://goo.gl/oH9EXp

N.B. Additional articles on the provision and delivery of PC during humanitarian crises or natural disasters noted in 26 November 2018 issue of Media Watch (#591, p.11-12). On the website of the European Association for Palliative Care, the author discusses ‘How do expatriate health workers cope with needs to provide PC in humanitarian emergency assistance? A qualitative study with in-depth interviews,’ published online in *Palliative Medicine*, 16 August 2018. [Noted in 20 August 2018 issue of Media Watch (#577, p.11)] https://goo.gl/tm7d1w

Effect of living wills on end-of-life care: A systematic review

JOURNAL OF AMERICAN GERIATRIC SOCIETY | Online – 3 December 2018 – All interventional and observational studies were included, excepting those with fictive cases. Included studies were conducted in adults with and without living wills, excluding individuals with specific psychiatric living wills. From 7,596 records identified, 28 observational studies were included, 19 conducted in the U.S., 7 in Europe, and 1 each in Canada and Australia. Place of death was assessed in 14 studies, life-sustaining treatments in 13, decision for restricted care in 12, and hospitalization in 8. Risk of bias was serious for 26 studies and moderate for 2. Twenty-one studies reported significantly less medical management for individuals with a living will, 3 reported more medical management, and the difference was not significant in 37. Methodological quality of included studies was insufficient to offer reliable results. The effect of living wills appears limited in view of the importance and direction of potential biases. Further studies including larger populations, considering main confounding factors, and documenting the real presence of a living will in medical records are necessary to reach stronger conclusions on the effect of living wills on end-of-life care. **Abstract:** https://goo.gl/SJEqAD

> **N.B.** See commentary on this study: 'Living wills: One part of the advance care planning puzzle,' *Journal of American Geriatric Society*, published online 3 December 2018. https://goo.gl/xhd8d5
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> Noted in Media Watch 1 January 2018 (#539, p.12):
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> - *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 December 2017 – **'Respecting Choices® and related models of advance care planning: A systematic review of published evidence.'** The authors found that there is a low level of evidence that Respecting Choices® (RC) and derivative models increase the incidence and prevalence of advance directive and Physician Orders for Life-Sustaining Treatment (POLST) completion. The evidence is mixed, inconclusive and too poor in quality to determine whether RC and derivative models change the consistency of treatment with wishes and overall health-care utilization in the end of life. **Abstract:** https://goo.gl/pnq22k
>
> **Related**
>
> - *GERIATRICS* | Online – 5 December 2018 – **'Acceptability of paper-based advance care planning to Inform end-of-life care provision for community dwelling older adults: A qualitative interview study.'** Using a paper-based approach to deliver streamlined advance care planning (ACP) and end-of-life care was a theme to emerge as a potential barrier, and highlighted problems with accessing paper-based documentation, accuracy and care co-ordination in the context of multidisciplinary team working. The value of technology in overcoming this barrier and underpinning ACP as a means to help simplify service provision, promote integrated professional practice and provide seamless care, was put forward as a way forward. **Full text:** https://goo.gl/TbCaxr

Quality of end-of-life care and its association with nurse practice environments in U.S. hospitals

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 2 December 2018 – The purpose of this study is two-fold: 1) To describe the quality of end-of-life care (EoLC) in U.S. hospitals from the perspective of hospital nurses; and, 2) To evaluate the relationship between the nurse practice environment and EoLC quality. 12,870 direct care registered nurses in 491 acute-care hospitals participated. Most gave their hospitals an unfavorable evaluation of EoLC overall (58%) and said patients often experience painful procedures that were unlikely to change their outcome (53%). The best predictor of poor quality was the nurse practice environment. Nurses in the best environments were 55% less likely than nurses in poor environments to rate their hospital's overall EoLC quality unfavorably… Quality of EoLC in U.S. hospitals is imperfect and is significantly worse in hospitals with poor nurse practice environments than in hospitals with the best environments. This study reinforces the importance of nurses in providing high-quality EoLC. **Abstract:** https://goo.gl/3KdSPS

Ten-year trends of palliative care utilization associated with multiple sclerosis patients in the U.S. from 2005 to 2014

JOURNAL OF CLINICAL NEUROSCIENCE, 2018;58:13-19. Patients with multiple sclerosis (MS) could benefit from palliative care (PC) perspectives both during relapses that lead to transient disability as well as later in the disease course when significant physical and cognitive disability have accrued. The national trends of PC utilization in MS patients increased by 120 times from 0.2% to 6.1% during 2005-2014, particularly with the dramatic single-year increase between 2010 (1.5%) and 2011 (4.5%). Moreover, the proportion of receiving PC in in-hospital death gradually increased from 7.7% in 2005 to 58.8% in 2014. PC in MS inpatients may affect hospital utilization and charges in different ways. Hospital PC was associated with increased length of stay and in-hospital death, but associated with decreased hospital charges. **Abstract:** https://goo.gl/T78dxv

Related

- *CONTINUUM*, 2018;24(6):1794-1799. **'End-of-life considerations and shared decision making in neurocritical care.'** Close cooperation and meaningful interaction must be achieved with family members so that the patient's "person can emerge" through discussions. This article highlights several caveats that can subvert this complex process, including the cognitive biases that affect both clinicians and surrogates. Impact, optimism, and gain-framing biases may be particularly relevant when considering patients who are receiving neurocritical care. Practitioners need to be cognizant of the distorting influences of these biases and make attempts to neutralize them. **Abstract:** https://goo.gl/LWfp4g

Noted in Media Watch 22 October 2018 (#586, p.16):

- *SEMINARS IN NEUROLOGY*, 2018;38(05):569-575. **'Neuropalliative care: A practical guide for the neurologist.'** Neuropalliative care is a new and growing field within neurology that focuses on improving the quality of life of patients with serious neurologic illnesses. While specialty-level palliative care (PC) training is available to interested neurologists, all neurologists can strive to provide primary PC for their patients. The authors describe the scope of neuropalliative care, define patient populations who may benefit from PC, and explore the communication and symptom management skills essential to PC delivery. **Abstract:** https://goo.gl/mjj32k

N.B. Selected articles on the role of PC in neurology noted in 19 February 2018 issue of Media Watch (#551, p.8). For additional articles specific to multiple sclerosis, Parkinson's disease and amyotrophic lateral sclerosis see the following back issues of the weekly report: respectively, 30 July 2018 (#574, p.11), 17 September 2018 (#581, p.13), and 27 August 2018 (#578, p.8).

Characteristics of a perinatal palliative care program over 10 years

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2018;56(6):e107-e108. Perinatal hospice is a relatively new component of pediatric palliative care (PC), which supports families who are expecting the birth of a child with life-threatening or life-limiting condition. Parents in this situation have unique needs and often experience emotional isolation following their child's loss. This study explores the characteristics of babies and families referred for perinatal hospice, and provides descriptive analysis of diagnosis, interventions and outcomes. The authors identified 78 cases of perinatal hospice. Fifty-one percent of patients were referred ante-natally and 49% post-natally. Referring physicians were most commonly neonatologists (47%), obstetricians (32%), or specialists in genetics/metabolics (12%). The average time between the diagnosis of a life-limiting condition and PC team referral was 4.5 weeks. In 25% of cases the baby was stillborn and in the remaining 75% of cases the child was born alive. Thirty babies (46%) received care in the neonatal intensive care unit after birth, and 20 (30%) had care at a pediatric hospice. Sixty-seven percent of antenatal referrals had a specialized birth plan which was used to direct care at the time of the baby's birth, while only 10% of post-natal referrals had this. In 84% of antenatal referrals, the baby received only comfort-focussed care after birth, while 54% of the post-natal referrals had resuscitation, including positive pressure ventilation and chest compressions. **Abstract:** https://goo.gl/3L2y22

Cont.

Noted in Media Watch 5 November 2018 (#588, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 November 2018 – **'Lasting legacy: Maternal perspectives of perinatal palliative care.'** Without a perinatal palliative care plan in place, the default treatment for infants with prenatally diagnosed life-limiting conditions is likely to be invasive and painful with often times minimal likelihood of long-term survival. Analysis of interview and focus group data revealed three themes: care, choice, and legacy. **Abstract:** https://goo.gl/tNveyz

Adding silver to the rainbow: Palliative and end-of-life care for the geriatric LGBTQ patient

JOURNAL OF PALLIATIVE MEDICINE | Online – 4 December 2018 – Lesbian, gay bisexual, transgender, and queer or questioning (LGBTQ) older adults have unique health care needs, especially in the palliative care (PC) and hospice setting. The authors present a male patient with metastatic ovarian cancer, admitted with worsening dyspnea, now at the end of life. Only his wife was aware of his identified gender, and non-disclosure was very important to him. As he continued to decline, the team navigated LGBTQ-sensitive care within the health care setting, insurance inequalities, and support and communication to his family. This case study summarizes clinical recommendations for the LGBTQ individual in the hospice and PC setting, suggesting how our patient's care may have been improved. With the changes in social acceptance and attitudes, the LGBTQ community has become more visible and their numbers appear to be growing. It is important, therefore, that hospice and PC providers be educated on their needs to provide competent and inclusive health care. **Abstract:** https://goo.gl/VfEhym

Noted in Media Watch 20 August 2018 (#577, p.13):

- *JOURNAL OF GERONTOLOGICAL SOCIAL WORK* | Online – 13 August 2018 – **'"Fear runs deep": The anticipated needs of LGBT older adults in long-term care.'** This study adds to the existing literature about the worries of older lesbian, gay, bisexual, and transgender (LGBT) adults as they anticipate long-term care. The results suggest that they seek LGBT-inclusive residential care settings that encompass two distinct yet related aspects of LGBT-affirmative care: the procedural (e.g., culturally competent skills and knowledge of practitioners) and the implicit (e.g., the values and mission of the organization). This paper identifies implications for practice, policy, and training. **Abstract (w. link to references):** https://goo.gl/pbBf7r

Addressing the needs of international patients at end of life in a tertiary care medical center

MAYO CLINICAL PROCEEDINGS, 2018;93(12):1698-1699. Effective communication is the cornerstone of the interactions among the patient, the physician, and the attendant health care system, especially so when the patient faces end-of-life (EoL) issues and decides on EoL care. Achieving such communication and an understanding of what the health care system meaningfully provides for EoLC care raises unique considerations for patients with diverse cultural, language, ethnic, and spiritual backgrounds. In their article … Partain *et al* describe several issues for consideration in the care of these patients.[1] These include the prevalence of advance care planning, advance directives, and full code status as well as potential barriers that exist to delivery of high-quality EoL care. Although patients travel abroad seeking care for many of the same reasons that domestic patients seek care (with hopes for an improvement in their condition or perhaps a cure), important differences affect the ultimate acceptance of and receipt of EoL services. A deeper understanding of these factors will be critical to the advancement of high-quality EoL care to patients from around the globe, about which little is currently known. Mayo Clinic serves as a global referral campus for patients with complex medical issues, due in part to the recognition of high-quality medical care as well as the perception from those around the world that medical care in the U.S. may represent a "beacon of hope." For these reasons, a variety of patient types seek care in the U.S., including those with complex, multisystem, treatment-refractory, or end-stage disease, often for the promise of new cutting-edge treatment modalities or treatment-specific expertise that may have limited availability in their home countries. **Full text:** https://goo.gl/r3razb

1. 'End-of-life care for seriously ill international patients at a global destination medical center,' *Mayo Clinical Proceedings*, 2018;93(12):1720-1727. **Abstract:** https://goo.gl/7YYufK

Community-led and/or focused initiatives to support family carers within a palliative care context: An integrative review

PALLIATIVE MEDICINE | Online – 6 December 2018 – Public health approaches to palliative care (PC) prioritise community-focused initiatives to support people with PC needs and their families. The nature and extent of these initiatives have not previously been reported. This integrative review identified only six community-focused and evaluated initiatives supporting family carers in the international PC research literature. Further evaluation is needed. However, appropriate evaluation methods and reporting require further discussion and debate between all stakeholders. Service users and communities themselves must be central to this process. **Abstract:** https://goo.gl/p9GoC2

Anticipatory prescribing of injectable medications for adults at the end of life in the community: A systematic literature review and narrative synthesis

PALLIATIVE MEDICINE | Online – 4 December 2018 – Anticipatory prescribing is a recommended and widespread practice in many countries, despite an inadequate knowledge base. Policy and practice are running ahead of the evidence, based largely on the belief of healthcare professionals that it reassures patients and their family carers, effectively controls symptoms and prevents crisis hospital admissions. The views and experiences of patients and their family carers have not been adequately investigated; nether has clinical effectiveness, cost-effectiveness, and safety. **Full text:** https://goo.gl/YQwwZk

> **N.B.** Additional articles on anticipatory prescribing of medications in end-of-life care noted in 1 May 2017 issue of Media Watch (#510, pp.12-13).

Early initiation of palliative care is associated with reduced late-life acute-hospital use: A population-based retrospective cohort study

PALLIATIVE MEDICINE | Online – 3 December 2018 – Early palliative care (PC) can reduce end-of-life (EoL) acute care use, but findings are mainly limited to cancer populations receiving hospital interventions. Few studies describe how early versus late PC affects EoL service utilization. The authors investigate the association between early versus late PC – hospital/community-based – and acute care use and other publicly funded services in the 2 weeks before death. They identified 230,921 decedents – cancer, frailty, and organ failure. 27% were early PC recipients and 13% were late; 45% of early recipients had a community-based initiation and 74% of late recipients had a hospital-based initiation. Early PC was associated with improved EoL outcomes. Late initiations were associated with greater acute care use, with the largest influence on organ failure and frailty decedents, suggesting potential opportunities for improvement. **Abstract (w. list of references):** https://goo.gl/GmGyXJ

Evidence of palliative care stigma: The role of negative stereotypes in preventing willingness to use palliative care

PALLIATIVE & SUPPORTIVE CARE | Online – 6 December 2018 – Although palliative care (PC) is critical to managing symptoms, pain, and transitions to end-of-life care among those facing serious or chronic illness, it is often underused, which may be due to stigma associated with PC representing giving up fighting one's illness. In study 1, those in the PC condition endorsed significantly higher levels of negative stereotypes about the patient, viewed the decision more negatively, and saw the patient as less afraid of death. In study 2, PC stigma was associated with less prospective usage of PC for self and for one's family member. This relationship was mediated by negative stereotypes about individuals receiving PC. Future research should examine stigma reduction as a potential intervention target to improve PC utilization. **Abstract (w. list of references):** https://goo.gl/59E3F2

PALLIMED
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Media Watch: Behind the Scenes
http://goo.gl/XDjHxz

Outcome dimensions in pediatric palliative care

PEDIATRICS | Online – 7 December 2018 – Most acute minor and moderate illness episodes unfold as a linear journey, from health to illness, and, one hopes, back again. In this simplest of illness models, outcomes exist along a single dimension, such as the length of illness or the probability of full recovery. As illness becomes more chronic or severe, the corresponding model of illness becomes more complicated as the dimensions of outcomes increases. Length of time away from normal activities or in the hospital, along with the probability of complications or survival, provide different views of outcomes. When the subjective aspects of the illness experience, such as symptom distress or quality of life, are incorporated into the illness model, the dimensionality of the model rises substantially. All of which is to say that just as a stick figure is not an accurate drawing of an individual human, the simple model of illness is not an accurate rendition of the real multidimensional disorder. Nevertheless, the simple model can be extraordinarily useful. Medical science progresses by working with tractable models of health and disease. **Abstract:** https://goo.gl/s7VV8G

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 December 2018 – **'Homeward bound: A case series of cross-cultural care at end of life, enhanced by pediatric palliative transport.'** For most families, the preferred location of death for their child is home, yet most children still die in the hospital. Many children with life-threatening and life-limiting illness are medically dependent on technology, and palliative transport (PT) can serve as a bridge from the ICU to the family's home to achieve family-centered goals of care. PT may also present an opportunity to prioritize cultural care and rituals at end of life which cannot be provided in the hospital. **Abstract:** https://goo.gl/LiJW8d

- *PEDIATRICS* | Online – 7 December 2018 – **'Instruments to measure outcomes in pediatric palliative care: A systematic review.'** Researchers in 15 of (2,150) articles used quantitative methods, and 9 were of moderate quality. Multidimensional outcomes included health-related quality of life, spiritual well-being, satisfaction with care and/or communication, perceived social support, and family involvement in treatment or place-of-care preferences. Interventions ranged from home-based to hospital and respite care. Only 15 instruments (of 23 reported) revealed some psychometric properties, and only 5 included patient-reported (child) outcome measures. **Abstract:** https://goo.gl/diBF26

Racial and ethnic differences in end-of-life care in the U.S.: Evidence from the Health & Retirement Study

SSM – POPULATION HEALTH | Online – 30 November 2018 – This study provides an analysis of end-of-life (EoL) circumstances of the American population. There are marked racial and ethnic disparities at the EoL, even when adjusting for a range of individual characteristics. The demand for culturally-sensitive EoL care will continue to rise due to a growing ethnically and racially diverse population of older adults. Efforts to reduce existing discrepancies should target both patients and healthcare professionals to ensure that new models of care accommodate the diverse needs of older adults. Securing these conditions for high-quality EoL care is likely to require dedicated support from governmental structures. The millions of Americans that deal with life-threatening conditions deserve access to adequate patient-centered EoL care. **Full text:** https://goo.gl/b7WSB3

N.B. Selected articles on racial disparities in the provision and delivery of EoL care in the U.S. noted in 16 July and 5 November 2018 issues of Media Watch (#572, p.5 and #588, p.8, respectively).

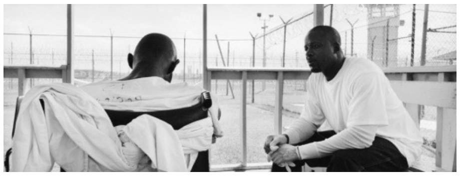


Photo: Lori Waselchuk. Philadelphia, PA

Prison Hospice: Backgrounder

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: https://goo.gl/dqwNBA

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL OF AMERICAN PHYSICIANS & SURGEONS*, 2018; 23(4):121-124. **'Physician-assisted suicide/physician-assisted death: The rise of lifeboat ethics.'** In discussions of the need to "bend down the cost curve," save resources, and thus achieve the goals of affordable and accessible care, there is the explicit or implicit question: "Does our society need to eliminate the hopelessly ill?" Progressives and socialists have created existing law and templates to do this, and the concept is becoming popular with Americans. According to recent polls, those favoring assisted suicide now clearly outnumber those who oppose it… Have the models of physician-assisted suicide (PAS or, now, physician-assisted death, PAD) in California, Colorado, Oregon, Vermont, Hawaii, Montana, Washington State, the District of Columbia, The Netherlands, Switzerland, Germany, and Canada provided evidence that these interventions have reduced costs and redistributed resources in a beneficial way? Canadians assert that "providing medical assistance in dying in Canada should not result in any excess financial burden to the healthcare system, and could result in substantial savings." However, the cost savings have not been realized in any of these models for a variety of reasons, and benefits have been illusory. **Download/ access full text at:** https://goo.gl/mtda7R

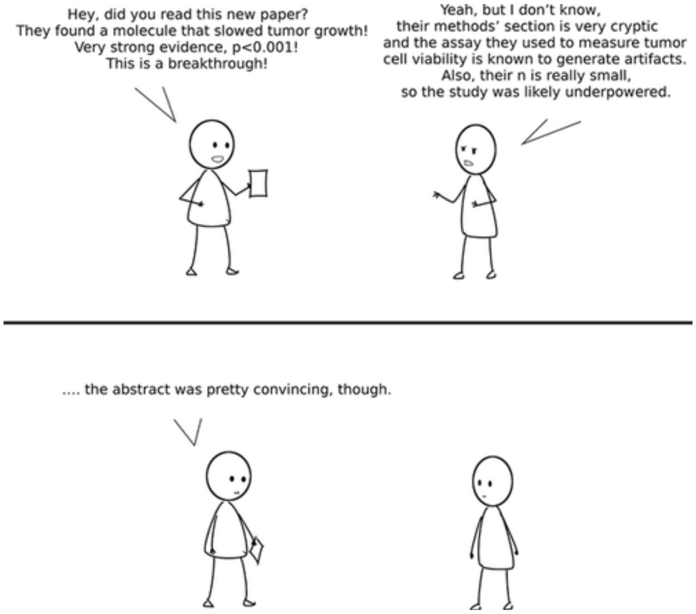
Extract from *Journal of American Physicians & Surgeons* article

Modern medicine can design better methods of caring for the dying without complicated governmental intervention. The need for access to adequate hospice care – to comfort care – without the need for political posturing, a rights argument, a faux ethic, and a legislative and regulatory mandate based on economic falsehoods, cannot be addressed without the expertise of the medical community.

Publishing Matters

To read more papers, or to read papers better? A crucial point for the reproducibility crisis

BIOESSAYS | Online – 28 November 2018 – The overflow of scientific literature stimulates poor reading habits which can aggravate science's reproducibility crisis. Thus, solving the reproducibility crisis demands not only methodological changes, but also changes in our relationship with the scientific literature, especially our reading habits. Importantly, this does not mean reading more, it means reading better. **Abstract:** https://goo.gl/euukqM



Media Watch: Editorial Practice

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

Distribution

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6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

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International

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

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

Asia

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

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

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

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

Cont.

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

[Scroll down to 'Additional Resources']

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

Europe

HUNGARY | Magyar Hospice Alapítvány: https://goo.gl/L7D2hw

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

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