Media Watch...

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

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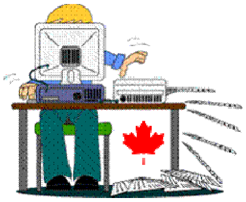


Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'Can specially trained community care workers effectively support patients and their families in the home setting at the end of life?' (p.11), in *Health & Social Care in the Community*.

Canada

Gaining a new perspective – and vocabulary – on old age

THE GLOBE & MAIL | Online – 23 November 2017 – Words are powerful. They have the ability to inspire. They also have the ability to stigmatize. In the health field, there's an increasing realization that the inappropriate choice of words in describing patients can be detrimental to their care – especially older individuals. Research suggests that the public tends to associate aging with decline and deterioration. That does not bode well for the future – given the fact that a growing proportion of the population is over the age of 65. So, the influential *Journal of the American Geriatrics Society* recently decided it's time to redefine aging. "Widespread negative assumptions about 'getting old' have led the public to take a fatalistic stance that there is not much to be done about aging," the journal's executives wrote in an editorial published in June.[1] In an effort to hit the reset button, they announced that: "words like (the) aged, elder(s), (the) elderly, and seniors should not be used" in their publication any more because such words "connote negative stereotypes." Instead, "older adults" or "older persons" are now the preferred ways to refer to those over the age of 65. By curbing the use of terms that reinforce stereotypes, it may lead to "a new understanding of aging and how increased longevity can help us contribute to our communities for as long as possible," Nancy Lundebjerg, chief executive officer of the American Geriatrics Society, said in an e-mail. That's certainly a lofty goal. But not everyone is convinced that all the words on the journal's prohibited list are particularly negative or harmful. https://goo.gl/Jk6UTa

1. 'When it comes to older adults, language matters: *Journal of the American Geriatrics Society* adopts modified American Medical Association style,' *Journal of the American Geriatric Society*, published online 1 June 2017. **Full text:** https://goo.gl/eJenW1

Noted in Media Watch 9 October 2017 (#533, p.16):

- *CURRENT ONCOLOGY REPORTS* | Online – 2 October 2017 – **'Using geriatric assessment strategies to lead end-of-life care discussions.'** Developing a roadmap for these conversations can be challenging. Patients and caregivers may have expectations that are not concordant with what is reasonably achievable if the patient is frail. Measuring baseline cognition, nutritional status, and physical function and discussing goals of care are all essential pieces of information that can be obtained through a comprehensive geriatric assessment. **Abstract:** https://goo.gl/7C7x1J

Cont.

Noted in Media Watch 17 April 2017 (#508, p.7):

- *CLINICS IN GERIATRIC MEDICINE* | Online – 6 April 2017 – **'Integrating quality palliative and end-of-life care into the geriatric assessment.'** Integrating quality palliative and end-of-life care (P&EoLC) into geriatric assessment can be a tremendous benefit to older adult patients and their families. Although the quality of P&EoLC for older adults has improved greatly, there are still many opportunities to improve the quality of life and function for older adult patients in the last few years of their life. **Abstract:** https://goo.gl/5vhdzr

N.B. Noted in the 6 February 2017 issue of Media Watch (#498, p.6) are additional articles on the common ground shared by geriatric and palliative medicines.

U.S.A.

In the woods and the shadows, street medicine treats the nation's homeless

PENNSYLVANIA | *The Washington Post* – 22 November 2017 – [Nurse Laura] LaCroix and [Brett] Feldman [a physician assistant who heads the "street medicine" program at Lehigh Valley Health Network] are part of a burgeoning effort to locate and take care of them no matter where they are – whether under bridges, in alleyways or on door stoops. Most of the time, members of Feldman's team provide basic primary care to people who live in dozens of encampments throughout eastern Pennsylvania's Lehigh Valley. During their street rounds, they apply antibiotic ointment to cuts, wrap up sprains and treat chronic conditions such as blood pressure and diabetes. But they also help people sign up for Medicaid, apply for Social Security disability benefits and find housing. Three or four times a month, they deal with individuals threatening to commit suicide. Many days, they simply listen to their patients, trying also to relieve emotional pain. https://goo.gl/umG2hm

street medicine institute

Extract from *The Washington Post* article

Street medicine was pioneered in this country in the 1980s and 1990s by homeless advocates Jim O'Connell in Boston and Jim Withers in Pittsburgh. Yet only in the past five years has it caught fire, with a few dozen programs becoming more than 60 nationwide. A recent conference on the topic in Allentown drew 500 doctors, nurses, medical students and others from 85 cities, including London, Prague and New Delhi. Most programs are started by non-profit organizations or medical students.

N.B. Street Medicine Institute website: https://goo.gl/9JrnWV

Noted in Media Watch 10 July 2017 issue of Media Watch (#520, p.9):

- *MEDSCAPE* | Online – 3 July 2017 – **'Homeless and dying in America: Facing the end of life alone.'** More than a million people face homelessness each year in the U.S., and these individuals often have multiple complex illnesses and co-morbid mental health conditions. Orchestrating care for the homeless population poses significant challenges. A major gap in knowledge exists regarding the symptoms experienced by homeless persons at or near the end of life – information that would help clinicians not only manage these symptoms but also assist homeless persons with advance care planning and decision-making around death and dying.[1] **Full text:** https://goo.gl/zS6BuL

    1. 'Homeless individuals approaching the end of life: Symptoms and attitudes,' *Journal of Pain & Symptom Management*, published online 30 December 2016. [Noted in Media Watch 2 January 2017 (#493, p.18)] **Abstract:** https://goo.gl/szzW4u

N.B. Selected articles on end-of-life care for the homeless are noted in the 15 March 2017 issue of Media Watch (#512, p.12).

Why Medicare patients are more likely to have end-of-life talks with their doctors

U.S. NEWS & WORLD REPORT | Online – 22 November 2017 – Planning for care at the end of a patient's life is an uncomfortable yet necessary conversation. Without it, a doctor won't know if the person wants to be resuscitated, placed in hospice or subjected to advanced treatments to prolong his or her life. It can also avoid costly treatments and family fights that, in hindsight, were unnecessary. Yet, even with physicians now being compensated for having these discussions with their aging patients, only a small portion of Medicare beneficiaries are receiving the counseling. At first blush, an adoption rate of around 1% seems very low, but experts say the number should start to increase in the months ahead. Many experts point to these results as an encouraging starting point. After all, it represents more than 500,000 people who didn't have these conversations in a substantive way before... https://goo.gl/LWXUWw

Specialist Publications

'Innovative models for high-risk patients use care coordination and palliative supports to reduce end-of-life utilization and spending' (p.11), in *Innovation in Aging.*

'Hospice care for patients with dementia in the U.S.: A longitudinal cohort study' (p.11), in *Journal of the American Medical Directors Association*.

Nursing home residents have little access to palliative care, study says

CALIFORNIA | *The Mercury News* (San Jose) – 20 November 2017 – About 70% of nursing home residents are eligible for palliative care (PC), but don't get the kind of support needed to relieve their symptoms and improve their quality of life (QoL)... In a survey of 228 residents in three northern California nursing homes between January and May 2015, University of California San Francisco researchers found that 157 patients (68.8%) were eligible for specialized medical care that focuses on improving QoL for patients with serious illness...[1] Of those, 47% had been diagnosed with Alzheimer's or dementia, and almost half had to be re-admitted to a hospital in the past year. Yet the report said none of the residents were receiving PC, and only two had hospice care. The researchers wrote that it's important to more quickly identify nursing home residents who would be eligible for PC. By 2030, 40% of all U.S. deaths are projected to occur in nursing homes, where care costs $136 billion annually. But studies have shown that nursing homes don't do a good job of keeping patients healthy, have a low family satisfaction, and often lead to burdensome and unnecessary care at the end of life. https://goo.gl/KkNQhR

1. 'Palliative care eligibility, symptom burden, and quality-of-life ratings in nursing home residents,' *JAMA Internal Medicine*, published online 20 November 2017. **Abstract:** https://goo.gl/J9qd8J

Noted in Media Watch 30 October 2017 (#536, p.14):

- *MEDICAL CARE* | Online – 24 October 2017 – **'Impact of nursing home palliative care teams on end-of-life outcomes: A randomized controlled trial.'** Nursing homes with palliative care (PC) teams had reduced rates of depressive symptoms, but not pain or hospitalizations. PC intervention was not equally effective for all outcomes and facilities. Reforms to create the environment in which effective PC can become broadly implemented are needed. **Abstract:** https://goo.gl/PSBmYn

Noted in Media Watch 21 August 2017 (#526, p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 August 2017 – **'Palliative care consults in U.S. nursing homes: Not just for the dying.'** Short- and long-stay nursing home (NH) residents with palliative care consults differed not only, in many respects, from NH residents generally, but also from each other. Despite these differences, half of short-stay and 57% of long-stay residents were alive six months after initial consults. **Abstract:** https://goo.gl/fNE6cX

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- DELAWARE | Delaware Public Media (Dover) – 20 November 2017 – **'Medical Society of Delaware will continue to use the term "physician-assisted suicide."'** The Medical Society of Delaware (MSD) is deciding to continue its policy opposing what they term as physician-assisted suicide, but some, including state legislators, want them to use the name – and support the practice of – medical aid in dying. There is a bill on the ready list for vote in the Delaware House of Representatives which would allow physicians to prescribe a lethal medication to terminally ill patients who request it. The proposed law would require a second opinion on the patient's prognosis of six months or less to live, verification the patient is of sound mind and body, and the lethal prescription must be self-administered. The bill is largely patterned after a law in Oregon which does not require doctors to participate in the aid in dying program. https://goo.gl/oKugme

Specialist Publications

'Accepting professional accountability: A call for uniform national data collection on medical aid in dying' (p.18), in *Health Affairs*.

International

End-of-life care in England

Parliamentary inquiry into children's palliative care choices

U.K. (England) | Together for Short Lives – 24 November 2017 – The All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care has launched an inquiry on the extent to which the government is meeting its end of life care choice commitment for babies, children and young people. The APPG is inviting written evidence submissions from young people, families, professionals, services, government, public bodies and others who can offer their views on the barriers and opportunities to improving children's palliative care choices in England. https://goo.gl/6o2yWm

Noted in Media Watch 20 November 2017 (#539, p.7):

- U.K. (England) | *The Daily Mirror* (London) – 11 November 2017 – **End-of-life care for terminally ill children slammed as "patchy and inconsistent"** Palliative care for tens of thousands of terminally ill children has been slammed as "patchy and inconsistent" by a leading charity.[1] While 93% of National Health Service clinical commissioning groups commission community children's nursing teams, just two thirds commission them to provide care out-of-hours and at weekends. https://goo.gl/X2pfuw

    1. 'Commission Children's Palliative Care in England,' Together for Short Lives, November 2017. **Download/view background information at:** https://goo.gl/bvWdap

Wales scraps charges to bury or cremate children in "momentous" step to help grieving families

U.K. (Wales) | ITV News (Cardiff) – 23 November 2017 – Parents who suffer the death of a child will no longer have to pay for their burial or cremation fees, the Welsh Government has announced. The move is intended to spare bereaved families from struggling with the sometimes considerable financial strain of funeral arrangements as they come to terms with their loss. Welsh first minister Carwyn Jones announced the Government has signed an agreement with local authorities to stop charging for the burial of children in future. It has made £1.5 million available to help meet the costs of the scheme, which will come into effect today. Funding will also be available to all other providers of cemeteries and crematoria in Wales who agree not to charge on the same basis. https://goo.gl/3eekgR

Barriers to China's hospice care development

CHINA | China Internet Information Center (Beijing) – 22 November 2017 – Despite government efforts to ensure care for the terminally ill, some hurdles need to be cleared to achieve full-fledged development. Statistics show there are a total of about 2,000 beds in Beijing's 30-plus hospice inpatient facilities, a number far from sufficient. According to an investigation starting from early October, no bed was accessible in a dozen hospices in Beijing and patients had to reserve them in advance. However, many patients died while waiting for admission. While most hospice inpatient facilities are crowded, some of the beds there are not being used by those who really need them. For example, 70% of the elders staying in Songtang Care Hospital are not suffering from any serious disease. The main factor causing the low utilization is an unclear standard of hospice patients. The hospice centers of some medical institutions, such as Beijing Fuxing Hospital, are exclusively for patients with late stage cancer, but many others have more inclusive standards. The Hospice Center of Peking University Shougang Hospital, for example, receives patients with disability, cardiac failure and late-stage cancer. Beijing United Family Rehabilitation Hospital and Beijing Wanshoukang Hospital are open to anyone needing rehabilitation. Beijing Haidian Hospital will assess whether a patient is permitted to stay according to the medical records and family situation. https://goo.gl/dZ3USz

Noted in Media Watch 31 July 2017 (#523, p.13):

- *THE ONCOLOGIST* | Online – 24 July 2017 – **'Development of palliative care in China: A tale of three cities.'** With a population of 1.3 billion, China is the most populous country in the world and cancer is the leading cause of death. However, only 0.7% of hospitals offer palliative care (PC) services. The authors describe the program development and infrastructure of the PC programs at three Chinese institutions, using these as examples to discuss strategies to accelerate PC access for cancer patients in China. **Full text (to access click on pdf icon):** https://goo.gl/ZwBaob

Korea sees first legitimate case of patient refusing life support

SOUTH KOREA | *The Korea Herald* (Seoul) – 22 November 2017 – In January last year, the National Assembly passed a law that allows terminally ill patients with no prospect of recovery to refuse life support. The patient in his 50s, who suffered from gastrointestinal cancer, refused to receive four life-prolonging treatments – CPR, mechanical ventilation, hemodialysis and anti-cancer drug administration – by signing a Physician Order for Life-Sustaining Treatment about a month ago. Even if patients stop life support, they continue to get nutrition, water and treatment to relieve pain. Thirteen hospitals began trial operations of end-of-life care (EoLC) last month to consult with terminally ill patients and their family members before the "well-dying" law takes effect in February next year. A total of 1,648 people, mostly healthy, have signed a advance medical directive (AMD), in which they specified whether they will receive life-sustaining treatment or hospice care when they are dying. Anyone aged 19 or older can sign an AMD. Medical experts say it will take some time for the EoLC system to be put in place, as hospitals lack professional counselors and the paperwork is excessive. https://goo.gl/8ittmL

Noted in Media Watch 20 June 2016 (#467, p.13):

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2016;19(2):99-108. **'Hospice palliative care in South Korea: Past, present, and future.'** Hospice and palliative care in Korea has developed steadily since its introduction in 1965. Currently, it is targeted only towards terminal cancer patients and their families, and the national health insurance scheme covers only inpatient hospice care for said patients. **Full text:** http://goo.gl/Aa6FL3

Europe's only Jewish hospice gives Holocaust survivors a dignified farewell

THE NETHERLANDS | Jewish Telegraphic Agency – 21 November 2017 – Immanuel Jewish hospice in Amsterdam ... is Europe's only Jewish hospice... While such facilities are common in the U.S. – the National Institute for Jewish Hospice, which was established in 1985 in New York, lists no fewer than 225 accredited Jewish hospice programs – they remain rare on the continent, where the Jewish community was decimated by the Holocaust. The Netherlands ... has 146 hospices nationwide with an average guest satisfaction rating of 9.1 out of 10. And whereas Immanuel's on-demand room service is a standout amenity, patients at other hospices receive similar conditions – all for a daily rate of less than $70 covered by the government or basic insurance policies. But Immanuel is the only hospice in Europe ... who keep kosher, although there are other hospitals with palliative programs that offer kosher food. They include [in the U.K.] the North London Hospice Group, which defines itself as Britain's first "multi-faith hospice." It's also the only hospice where the staff and volunteers "already know the special issues connected to caring for the generation of Holocaust survivors," said Sasja Martel, the institution's founding director. That's crucial, she said, "because at the last stage of life, it's often too late to start explaining" what those special issues are. https://goo.gl/xrjc9Q

Noted in Media Watch 27 April 2015 (#407, p.5):

- U.S. | *The Jewish Week* (New York) – 21 April 2015 – **'Caring for Holocaust survivors at life's end.'** It is critical that Holocaust survivors' voices be heard and that the clinicians and caregivers exercise a language of listening because that is how trust is built. Important, too, is educating third parties such as social workers and other professional caregivers to facilitate these difficult conversations so care plans can be tailored to Holocaust survivor need – assuring control over choice, and meeting them where they are religiously and spiritually. https://goo.gl/VVm46s

End-of-life study points to healthcare shortcomings

SWITZERLAND | Swissinfo.com (Bern) – 21 November 2017 – The specific care needs of elderly patients dying in Swiss hospitals and nursing homes are not adequately met, a Swiss Science Foundation study has found.[1] Most people in Switzerland die in a hospital or nursing home. But at the end of their lives their basic needs are not given sufficient consideration and there is a lack of coordination among health professionals, resulting in fragmented care. These are the main of the five-year 'End of Life' national research programme, which comprises 33 projects looking at dying in Switzerland. Palliative care ... could help improve the current situation, the study's authors concluded. The high costs of health treatment in the final stages of someone's life are frequently discussed in Switzerland. A recent study by the KOF Swiss Economic Institute said increasing numbers of elderly people plus the stable Swiss economy had resulted in a 4.1% increase in health care expenditures this year.[2] The new Swiss Science Foundation study found that the costs associated with dying were typically lower for older people than for younger people. One of the reasons it put forward is that older people are less likely to die in a hospital... https://goo.gl/Cz8di4

FNSNF
Fonds national suisse
Schweizerischer Nationalfonds
Fondo nazionale svizzero
Swiss National Science Foundation

1. 'Synthesis Report of National Research Program: End of Life,' Swiss Science Foundation, Bern, 2017. **Download/view at:** https://goo.gl/gwxV8q

2. 'KOF Forecasts of Swiss Health Care Expenditures,' KOF Swiss Economic Institute, Zurich, November 2017. **Download/view (German language version) at:** https://goo.gl/b8bFSK

N.B. Selected articles on palliative and end-of-life care in Switzerland are noted in the 6 February 2017 issue of Media Watch (#498, pp.15-16).

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.19.

End-of-life care in Australia

Health system "fails the dying": Myths "shroud" end-of-life care

AUSTRALIA (New South Wales) | *The Australian* (Surry Hills) – 20 November 2017 – It is a "myth" that more Australians would prefer to die at home and what they really want and need is access to better and more comprehensive palliative care (PC) in hospitals, a report says.[1] The Centre for Independent Studies report ... says that of the 130,000 Australians who should have received PC last year, only 14,300 did, raising questions about how hospitals will accommodate the needs of an ageing population. It says Australia's health system has failed to evolve in line with increasing life spans and patient needs where the majority of elderly Australians now die from chronic disease. Author Jessica Borbasi argues part of the problem is the way Medicare payments are structured and said a rethink of the fractured system is required. While the report acknowledges medicine should be "commended for providing unprecedented longevity," it argues this has led to deaths which are often "ill-managed and expensive" with dementia set to surpass heart disease as the leading cause of death. https://goo.gl/fWKJ4X

Specialist Publications

'Reducing hospital admissions in remote Australia through the establishment of a palliative and chronic disease respite facility' (p.9), in *BMC Palliative Care*.

1. 'Life Before Death: Improving Palliative Care for Older Australians,' Centre for Independent Studies, Sydney, New South Wales, November 2017. **Download/view at:** https://goo.gl/t3jHns

N.B. Recent articles on palliative and end-of-life care in Australia are noted in the following issues of Media Watch: 6 November (#537, p.4); 23 October (#535, p.6); 9 October (#533, p.5); 25 September (pp.6,16); and, 18 September (#530, p.10).

Noted in Media Watch 12 October 2015 (#431, p.9):

- *BMC MEDICINE* | Online – 9 October 2015 – **'Is dying in hospital better than home in incurable cancer and what factors influence this? A population-based study.'** Four factors explained 91 % of home deaths: 1) Patient's preference; 2) Relative's preference; 3) Home palliative care; 4) Or district/community nursing. The propensity of death at home also increased when the relative was aware of incurability and the patient discussed his/her preferences with family. Dying in hospital was associated with more hospital days, fewer general practitioner (GP) home visits, and fewer days taken off work by relatives. Adjusting for confounders, patients who died at home experienced similar pain levels but more peace in their last week of life. **Full text:** https://goo.gl/Dm9G3d

- *BRITISH MEDICAL JOURNAL* | Online – 7 October 2015 – **'Is home always the best and preferred place of death?'** Focusing on place of death as the key indicator of quality in end-of-life care distracts attention from the experience of dying for patients and their families. Evidence suggests that place of death is not the over-riding priority. Control of symptoms, especially pain, and being accompanied by loved ones are more important. When patients wish to die at home, every effort should be made to achieve this outcome. However, until resources are in place to adequately and equitably support home deaths, the current promotion of patient choice risks raising expectations that are not realised. There are many reasons why patients may not wish to die at home. **Abstract:** https://goo.gl/fdVKCy

Noted in Media Watch 7 September 2015 (#426, p.16):

- *PALLIATIVE MEDICINE* | Online – 1 September 2015 – **'Palliative care in hospital: Why is it so difficult?'** Care of the dying used to be the bread and butter of family doctors – why and where has that confidence gone? At the same time, families are not available or confident to care, community services are fragmented, we do not talk about dying, and we do not prepare or plan ahead. The end result is that thousands of people are admitted to hospital every day, and culture and systems make it very difficult to escape. Studies have suggested that many who are in hospital could be supported elsewhere – however, this depends on citizens, health services and social care working much more cohesively together. **Full text:** https://goo.gl/fpvbRM

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (England & Wales) | The Conversation – 23 November 2017 – **'Why doctors need to improve the way we discuss assisted dying.'** Assisted dying can be a divisive and polarising subject. But there is one aspect on which most people probably agree – the need to improve the conversations people have about death. At the moment, there is uncertainty in the U.K. regarding what people – especially health professionals – can and cannot say when the topic of assisted dying comes up. Conversation can become especially stilted when it turns to patients obtaining the medical documentation required for an assisted death abroad. The situation requires clarification. Currently, if a doctor in the U.K. writes a specific report to help with an assisted death abroad (three organisations in Switzerland accept U.K citizens.), the General Medical Council (GMC) may view this as a "fitness to practice" issue. However, if a doctor provides copies of medical records, even with the knowledge that they will be used for an assisted death, it is not a fitness to practice issue. The GMC's position is that this would be "too far removed from the act of suicide to constitute encouragement or assistance." Yet the doctor can still refuse this request for documentation. (The patient can then appeal to the information commissioner under the Data Protection Act 1998, but this may be unsuccessful.) https://goo.gl/YRA8pX

- AUSTRALIA (Victoria) | ABC News (Melbourne) – 22 November 2017 – **'Euthanasia in Victoria: How the state's assisted laws will work.'** Victoria's Upper House has passed legislation to introduce historic laws to allow doctor-assisted dying. The bill will return to the Lower House for ratification before becoming law. Voluntary assisted dying will only be available to Victorians who are over the age of 18 and capable of making decisions. They must be suffering from an incurable illness, which causes intolerable suffering, and be expected to live for less than six months. Mental illness and disability alone are not grounds for access to assisted dying, but people who meet the criteria and also have a mental illness or disability will not be denied access. https://goo.gl/ebZfzs

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.

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.

Specialist Publications

End-of-life care in Canada

Bereaved family members' perceptions of the quality of end-of-life care across four types of inpatient care settings

BMC PALLIATIVE CARE | Online – 25 November 2017 – A cross-sectional mail-out survey was conducted of bereaved family members of patients who had died in extended care units, intensive care units, medical care units (MCU), and palliative care units. 1,254 death records were screened and 712 bereaved family caregivers were identified as eligible, of which 558 (who were initially contacted by mail and then followed up by phone) agreed to receive a questionnaire and 388 returned a completed questionnaire (response rate of 70%). Measures included satisfaction with end-of-life care (CANHELP – Canadian Health Care Evaluation Project – family caregiver bereavement version; scores range from 0 = not at all satisfied to 5 = completely satisfied), grief (TRIG – Texas Revised Inventory of Grief), optimism (Life Orientation Test – Revised) and resilience (The Resilience Scale). Family members experienced significantly lower satisfaction in MCU relative to other settings... Statistically significant differences were observed for CANHELP subscales of "doctor and nurse care," "illness management," "health services" and "communication." **Full text:** https://goo.gl/r9t6tR

Journal Watch

'Federal Trade Commission halts the deceptive practices of academic journal publishers' (p.18), in U.S. Federal Trade Commission Bulletin.

'What should we do about predatory publishing?' (p.19), in *European Science Editing.*

'A call for clarity and quality in medical writing' (p.19), in *Canadian Medical Association Journal.*

Noted in Media Watch 24 November 2014 (#385, p.13):

- *PLOSONE* | Online – 17 November 2014 – **'Factors affecting family satisfaction with inpatient end-of-life care.'** The Canadian Health care Evaluation Project bereavement questionnaire was mailed to the next-of-kin of recently deceased inpatients to seek factors associated with satisfaction with end-of-life care (EoLC). Nearly three-quarters of recently deceased inpatients would have preferred an out-of-hospital death. Intensive care units were a common, but not preferred, location of in-hospital deaths. Family satisfaction with EoLC was strongly associated with their relative dying in their preferred location. **Full text:** https://goo.gl/YWtd3b

Reducing hospital admissions in remote Australia through the establishment of a palliative and chronic disease respite facility

BMC PALLIATIVE CARE | Online – 21 November 2017 – There are limited respite services for palliative care patients and their families in the Northern Territory (NT). The high prevalence of complex chronic diseases, limited access to primary care services, and the poor living situations of many Aboriginal and Torres Strait Islander Australians result in high hospitalisation rates and pressure on tertiary health services. Palliative Care NT identified a need for a flexible, community based, culturally appropriate respite service in Alice Springs. It was of particular interest to assess the impact of the respite service on the extent to which hospital resources were accessed by this population of patients. Overall, there was a mean cost saving of $1,882.50 per episode for hospital admissions with a reduction in hospital admissions, mean length of stay, intensive care unit hours, and ventilator hours. The establishment of the respite service has met an important and unmet need in Alice Springs: provision of respite where none has existed before. **Full text:** https://goo.gl/zLtszv

N.B. An early version of this article was noted in the 25 July 2016 issue of Media Watch (#472, p.5). Additional articles on the provision and delivery of palliative and end-of-life care in rural and remote regions of Australia are noted in the 11 July 2016 issue of Media Watch (#470, pp.9-10).

Cont.

Noted in Media Watch 10 July 2017 (#520, p.13):

- *MEDICAL JOURNAL OF AUSTRALIA*, 2017;207(1):39. '**The gap reversed: A review of site of death in the Top End.**' Studies have documented the critical importance for indigenous people from rural and remote areas of "finishing up" (the culturally appropriate reference to death and dying) on "country" (ancestral community and lands). Transferring sacred knowledge, providing culturally appropriate care, and returning their "animal spirit" to the land are all facilitated by dying on country. Finishing up on country in rural and remote Northern Territory (NT) usually takes place in dwellings in the person's ancestral community and lands, either in their own home or the home of a relative or close community member who has assumed responsibility for their care. Territory Palliative Care Top End is the sole provider of palliative care services to the Top End of the NT. **Abstract:** https://goo.gl/gDi8fq

Demands and requests for "inappropriate" or "inadvisable" treatments at the end of life: What do you do at 2 o'clock in the morning when …?

BRITISH JOURNAL OF ANAESTHESIA, 2017;119(Suppl 1):i90-i98. In an era when healthcare has become increasingly complex and patient expectations are higher than ever before, we can find the decision-making process for patients, potentially at the end of their lives, increasingly difficult. In the shift from paternalism to patient choice, we can struggle to know what to do when faced with a patient, their family, or both requesting or demanding inadvisable, inappropriate, or futile treatments. It can feel as if we are being asked to subject patients to intrusions and interventions that "just feel wrong." The authors look at how ethical frameworks, legal statute, case law, and professional guidance, as they apply in the U.K., interact when we make these decisions, and they discuss some of the conflicts and challenges that such guidance pose. **Full text:** https://goo.gl/cKDpsh

N.B. Selected articles on medical futility are noted in the 23 October 2017 issue of Media Watch (#535, p.6).

Managing the nutritional needs of palliative care patients

BRITISH JOURNAL OF NURSING | Online – 23 November 2017 – The nutritional needs of patients receiving palliative care should be routinely assessed, taking into account disease trajectory and nutrition-related symptoms. The social and emotional aspects of eating and drinking should also be acknowledged; as should the distress that weight loss and anorexia engenders in patients and their families. Practical strategies to optimise nutritional intake are discussed. Open and sensitive communication of patients' needs and wishes is essential, especially when discussing complementary nutrition approaches. A holistic, multidisciplinary approach is key to meeting nutritional needs, and the goals of nutritional intervention should be regularly reviewed in the light of disease progression. **Abstract:** https://goo.gl/hHqnfz

Noted in Media Watch, 19 December 2011 (#237, p.12):

- *PSYCHO-ONCOLOGY* | Online – 8 December 2011 – '**Hydration and nutrition at the end of life: A systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff.**' Decrease in oral intake, weight loss, and muscular weakness in the last phases of a terminal illness, particularly in the context of the cachexia-anorexia syndrome, can be an important source of anxiety for the triad of patient, family, and health staff. The present literature review examines the emotional impact of reduced oral intake as well as perceptions and attitudes toward assisted nutrition and hydration for terminally ill patients at the end of life, among patients, family, and health care staff. **Abstract:** http://goo.gl/X71Dr8

Back Issues of Media Watch @

Palliative Care Network-e: http://goo.gl/8JyLmE
International Palliative Care Resource Center: http://goo.gl/frPgZ5

End-of-life care in Australia

Can specially trained community care workers effectively support patients and their families in the home setting at the end of life?

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 21 November 2017 – Recognising that patients and their families may not have the support they need to enable end-of-life care (EoLC) at home, a consortium of care providers developed, and received funding to trial, the Palliative Care Home Support Program (PCHSP) across seven health districts in New South Wales, Australia. The programme aimed to supplement EoLC in the home provided by existing multidisciplinary community palliative care (PC) teams, with specialist supportive community care workers (CCWs). An evaluation of the service was undertaken, focussing on the self-reported impact of the service on family carers (FCs), with triangulation of findings from community PC teams and CCWs. Service evaluation data were obtained through postal surveys and/or qualitative interviews with FCs, community PC teams and CCWs. FCs also reported the experience of their loved one based on 10 items drawn from the Quality of Death & Dying Questionnaire (QODD). The support provided by CCWs was valued by FCs for: enabling choice (i.e., to realise EoLC in the home); providing practical assistance ("hands-on"); and, for emotional support and reassurance. This was corroborated by community PC teams and CCWs. Responses by FCs on the QODD items indicated that in the last week of life effective control of symptoms was occurring and quality of life was being maintained. A notable benefit of the PCHSP model, which provided specific PC vocational training to an existing community care workforce, was a relatively rapid increase in the PC workforce across the state. **Abstract:** https://goo.gl/qwUxY1

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

Innovative models for high-risk patients use care coordination and palliative supports to reduce end-of-life utilization and spending

INNOVATION IN AGING | Online – 20 November 2017 – Three models that received Health Care Innovation Awards from the Centers for Medicare & Medicaid Services aimed to improve quality of care and reduce cost through the use of innovative care coordination models. This study explores the total cost of care and selected utilization outcomes at the end-of-life for these innovative models, each of which enrolled adults with multiple chronic conditions and featured care coordination with advance care planning (ACP) as a component of palliative care. These included a comprehensive at-home supportive care model for persons predicted to die within a year and two models offering ACP in nursing facilities and during care transitions. Comparing participants in each model who died during the study period to matched comparators, two of the three models were associated with significantly lower costs in the last 90 days of life ($2,122 and $4,606 per person), and the third model showed non-significant differences. Two of the three models encouraged early hospice entry in the last 30 days of life. For the comprehensive at-home supportive care model, the authors observed aggregate savings of nearly $19 million over the study period. One care transition model showed aggregate savings of over $500,000 during the same period. Potential drivers of these cost savings include improved patient safety, timeliness of care, and caregiver support. **Full text:** https://goo.gl/GKfwHq

Related

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 16 November 2017 – **'Hospice care for patients with dementia in the U.S.: A longitudinal cohort study.'** 7,328 patients [i.e., patient population studied] had a primary diagnosis of dementia. Hospices caring for patients with dementia were more likely to be for-profit, larger sized, provide care for more than 5 years, and serve a large percentage of nursing home patients. Patients with dementia were less likely to disenroll from hospice in conjunction with an acute hospitalization or emergency department visit and more likely to disenroll from hospice after long enrollment periods as compared with patients without dementia. **Abstract:** https://goo.gl/JXm3yS

Cont.

Noted in Media Watch 20 November 2017 (#539, p.3):

- U.S. (Minnesota) | RAC Monitor (St. Paul) | Online – 16 November 2017 – **‘“Oh God, I have lost myself”: Palliative care and Alzheimer’s dementia.’** Those stricken with Alzheimer’s dementia (AD) die twice. First, they experience the death of who they are. An estimated 5.5 million people are living with AD. A terminal diagnosis of AD is fraught with obstacles for those who want to control the way they die or family members who want to intervene with palliative care. **Full text:** https://goo.gl/qMa9mh

Ageing prisoners: An introduction to geriatric healthcare challenges in correctional facilities

INTERNATIONAL REVIEW OF THE RED CROSS | Online – 17 November 2017 – The rise in the number of older prisoners in many nations has been described as a correctional “ageing crisis” which poses an urgent financial, medical and programmatic challenge for correctional health-care systems. In 2016, the International Committee of the Red Cross hosted a conference entitled ‘Ageing and Imprisonment: Identifying the Needs of Older Prisoners’ to discuss the institutional, legal and health-care needs of incarcerated older adults, and the approaches some correctional facilities have taken to meeting these needs. This article describes some of the challenges facing correctional systems tasked with providing health care to older adults, highlights some strategies to improve their medical care, and identifies areas in need of reform. It draws principally on research and examples from the U.S. to offer insights and recommendations that may be considered in other systems as well. **Abstract:** https://goo.gl/FZWhMY

Palliative Care Network

Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 November 2017) can be downloaded/viewed at: https://goo.gl/YLckx6

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 November 2017 – **‘End-of-life care in imprisoned persons.’** In 2014, there were 2,224,400 incarcerated people in the U.S. In 2013, 4,446 inmates died while in custody of local or state prisons. Suicide and heart disease were the top two causes of death, at 34% and 27% respectively. While the age distribution of imprisoned persons has not changed over time, the age of prison populations has increased by 80% between 2000 and 2009. Additionally, deaths of incarcerated people have been demonstrated to occur at a younger chronological age when compared to the general population. **Abstract:** https://goo.gl/YzNHm7

Care planning for inpatients referred for palliative care consultation

JAMA INTERNAL MEDICINE | Online – 20 November 2017 – What are the characteristics of patients referred to inpatient palliative care (PC) consultation teams for advance care planning (ACP) or goals of care (GoC) discussions, what ACP/GOC needs are identified, and what are the outcomes? Findings in this study of 73,145 patients in inpatient PC teams, a need for ACP/GOC was the most common reason for inpatient PC consultation, and ACP/GOC needs were frequently identified even when the consultation request was for other reasons. During PC consultation, surrogates were identified and patients’ preferences regarding life-sustaining treatments were updated; however, only a minority of patients completed legal forms to document their preferences. **Abstract:** https://goo.gl/FLxUr5

Related

- *PALLIATIVE MEDICINE* | Online – 20 November 2017 – **‘Understanding how a palliative-specific patient-reported outcome intervention works to facilitate patient-centred care in advanced heart failure: A qualitative study.’** Patient-reported outcome measures are proposed to facilitate patient-centred care. Three key themes were identified: 1) Identification of unmet needs; 2) Holistic assessment; and, 3) Patient empowerment. The intervention impacted on processes of care by enabling a shared understanding of patients’ symptoms and concerns, facilitating patient–nurse communication by focusing on these unmet needs and empowering patients to become more involved in clinical discussions. **Abstract:** https://goo.gl/aECPSX

Mainstreaming genetics in palliative care: Barriers and suggestions for clinical genetic services

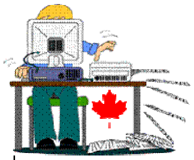
JOURNAL OF COMMUNITY GENETICS | Online – 20 November 2017 – Palliative healthcare professionals (PHCPs) frequently do not refer their eligible patients for genetic testing. After the death of the affected individual, clinically relevant information for family members is lost. In previous research, PHCPs stated that the end-of-life setting is not appropriate to discuss genetic issues. It is unclear if this has changed due to increasing awareness of genetics in the media and efforts to mainstream genetic testing. Semi-structured interviews of PHCPs were analysed by thematic analysis. Participants reported feeling unfamiliar with the role of clinical genetics services, and did not feel confident in addressing genetic issues with their patients. A lack of scientific knowledge and unawareness of existing infrastructure to support their patients were cited. Many stated that palliative patients are interested in exploring a potential hereditary component to their disease, and acknowledged the potential for psychological benefit for their patients and their families. Most stated that addressing genetics fits within their skill set, but expressed concern about issues of consent, logistical difficulties, and ethical dilemmas. These perceptions differ considerably from those reported in existing literature. Importantly, each participant stated that the potential benefits of addressing genetic issues outweighed the potential for harm in most cases. These results suggest a need for clinical genetics staff to develop closer links with their local PHCPs and to provide education. Clinical psychologists may also be a helpful resource to address PHCPs' concerns. **Abstract:** https://goo.gl/yXYgBQ

Nudging, informed consent and bullshit

JOURNAL OF MEDICAL ETHICS | Online – 16 November 2017 – Some philosophers have argued that during the process of obtaining informed consent, physicians should try to nudge their patients towards consenting to the option the physician believes best, where a nudge is any influence that is expected to predictably alter a person's behaviour without (substantively) restricting her options. Some proponents of nudging even argue that it is a necessary and unavoidable part of securing informed consent. The author argues that nudging is incompatible with obtaining informed consent. He assumes informed consent requires that a physician tells a patient the truth about her options and argues that nudging is incompatible with truth-telling. **Abstract:** https://goo.gl/bX8yfD

Noted in Media Watch 20 March 2017 (#504, p.7):

- *THE HASTINGS REPORT*, 2017;47(2):32-38. '**Justifying clinical nudges.**' The most straightforward justification for nudge interventions is that they help people bypass their cognitive limitations – for example, the tendency to choose the first option presented even when that option is not the best for them – thereby allowing people to make choices that best align with their rational preferences or deeply held values. **Abstract:** https://goo.gl/mDEMxg



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

Towards a fully-fledged integration of spiritual care and medical care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 20 November 2017 – The authors aim to set out current problems that hinder a fully-fledged integration of spiritual and medical care that address these obstacles. They discuss the following: 1) Spiritual care requires a clear and inclusive definition of spirituality; 2) Empirical evidence for spiritual care interventions should be improved; 3) Understanding patients' experiences of contingency is paramount to deliver effective spiritual care; 4) Attention to spiritual needs of patients is a task for every health care practitioner; and, 5) Courses on spirituality and spiritual care should be mandatory in the medical curriculum. Current problems might be overcome by speaking each other's language, which is crucial in interdisciplinary research and in good interdisciplinary collaboration. Using a clear and inclusive definition of spirituality and substantiating spiritual care using medical standards of evidence based practice is a way to speak each other's language and to increase mutual understanding. Furthermore, including spirituality in the medical curriculum would raise awareness of medical practitioners for their task of attending to patients' spiritual needs and, subsequently, to better, more and appropriate referral for spiritual care. **Abstract:** https://goo.gl/sq8Nup

Being whole

PALLIATIVE & SUPPORTIVE CARE | Online – 20 November 2017 – We are all broken. We are all imperfect. We are all mortal. We all experience loss, limitations, uncertainty. Death is the ultimate limitation and our mortality is our ultimate fragility and imperfection. Our imperfection teaches us empathy; to be capable of love. And our imperfection is what makes it possible for others to love us, because no one can love a perfect human being (we don't exist).Our imperfection is the gift that allows us to love and be loved in return. The essence of the human experience is connection. Connection to ourselves, and to each other, through love and care. Connection to the continuum of time and legacy (the past, present, and future), and finally the connection to something greater than ourselves (transcendence: connecting to nature, love, beauty, compassion, perhaps some concept of a creator or God). It is when we are disconnected from those we love and who/what we care about that we experience the despair of no longer "being whole." It is through re-establishing these connections, and ultimately through transcendence and connection with something greater than ourselves that we can re-experience "being whole." **Full text (to access click on pdf icon):** https://goo.gl/p4J7uu

Noted in Media Watch 24 July 2017 (#522, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2017;54(3):428-440 (first published online 18 July 2017). **'State of the science of spirituality and palliative care research: Research landscape and future directions (Part 1).'** Spirituality frequently plays a central and complex role in patients' and families' experiences of incurable illness, including influencing quality of life and medical decision-making. Advances in this field that expand the understanding of the relationships between spirituality and health outcomes and lead to the rigorous development of interventions to address patient and family spiritual needs hold tremendous potential for improving a comprehensive approach to care in serious illness. **Abstract:** https://goo.gl/uNe8G3

N.B. 'Screen, assessment and interventions (Part 2'): https://goo.gl/EiWqdd

End-of-life care in Japan

"What I did for my loved one is more important than whether we talked about death": A nationwide survey of bereaved family members

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 November 2017 – Actions in preparation for death and talks about death between advanced cancer patients and their families are considered essential to achieve a good death. However, little is known about the prevalence of such actions compared with talks and their association with bereaved families' psychological morbidity. Most families [i.e., survey respondents] acted in preparation for death, and those who acted were less likely to suffer depression or complicated grief. **Abstract:** https://goo.gl/FxVGDA

Patterns of care at the end of life for children and young adults with life-threatening complex chronic conditions

JOURNAL OF PEDIATRICS | Online – 21 November 2017 – In this cross-sectional study the majority of children with life-threatening complex chronic conditions (LT-CCCs) died in the hospital (62.7%) with more than one-half (53.3%) dying in the intensive care unit. Those with static encephalopathy, congenital and chromosomal disorders, and pulmonary disorders were significantly less likely to die at home compared with those with progressive central nervous system (CNS) disorders. Almost 50% of patients died after withdrawal or withholding of life-sustaining therapies, 17.5% died during active resuscitation, and 36% died while receiving comfort care only. The mode of death varied widely across LT-CCCs, with no patients with pulmonary disorders dying receiving comfort care only compared with 66.7% of those with CNS progressive disorders. A majority of patients had palliative care (PC) involvement (79.3%); however, there was distinct variation in receipt of PC across LT-CCCs, with patients having CNS static encephalopathy and pulmonary disorders significantly less likely to have PC involvement than those with CNS progressive disorders. **Abstract:** https://goo.gl/7NCFxQ

Perinatal and neonatal palliative/hospice care

The latest issue of the Children's Project on Palliative/Hospice Services (ChiPPS) e-journal focuses on perinatal and neonatal palliative and hospice care. **Download/view at:** https://goo.gl/GPH48x

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 November 2017 – **'Children with intellectual disability and hospice utilization: The moderating effect of residential care.'** The findings [of this study] highlight the important role of residential care in facilitating hospice enrollment for children with intellectual disability (ID). The odds of children with ID in residential care enrolling in hospice care were 3 times higher than their counterparts in their last year of life. Residential care promoted hospice enrollment among children with ID. The interaction between ID and residential care was not related to hospice length of stay. Residential care did not attenuate or intensify the relationship between ID and hospice length of stay. **Abstract:** https://goo.gl/Ztr6Uv

  Noted in Media Watch 28 August 2017 (#527, p.10):

  - *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES* | Online – 23 August 2017 – **'Paediatric palliative care and intellectual disability: A unique context.'** This study describes the complex care of children with life-limiting conditions and intellectual disability (ID) by means of a literature synthesis and commentary with "best-practice" guide. As few articles concerning children with ID and palliative care needs were identified by formal systematic review, the authors' expert consensus group has drawn from the paediatric palliative, oncology and adult ID literature to highlight common clinical challenges encountered in the day-to-day care of children with ID and life-limiting conditions. **Abstract:** https://goo.gl/sPB6vw

- *BMC PALLIATIVE CARE* | Online – 25 November 2017 – **'A scoping review of palliative care for children in low- and middle-income countries.'** Ninety-eight percent of children needing palliative care (PC) live in low- and middle-income countries (LMICs), and almost half of them live in Africa. In contrast to the abundance of data on populations in high income countries, the current data on populations in LMICs is woefully inadequate. Although the authors found limited evidence in this review, they identified common challenges such as the need for further training for health workers and greater availability of opioid analgesics. **Full text:** https://goo.gl/BdGwRM

- *CURRENT OPINION IN PEDIATRICS* | Online – 17 November 2017 – **'Pediatric palliative oncology: The state of the science and art of caring for children with cancer.'** This review focuses on advancements within several key areas of the field, specifically regarding investigation of the communication needs and preferences of patients and families, exploration of educational initiatives and interventions to teach pediatric palliative oncology (PPO) principles to clinicians, study of patient-reported and parent-reported tools to better assess and manage refractory symptoms, and development of novel models to integrate palliative care within pediatric oncology. Abstract: https://goo.gl/WSXpgJ

Serious incidents after death: Content analysis of incidents reported to a national database

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE | Online – 23 November 2017 – Serious incidents in the management of deceased patient remains have significant implications for families, hospitals and the health service more broadly. The findings of this study serve as a warning to those responsible for the management of mortuary services of the significant risks inherent in such services and the potentially devastating incidents that can occur if these risks are not mitigated and errors allowed to go unchecked. It also highlights areas that system improvement efforts can usefully be targeted in and approaches that have been shown to be successful in other areas of healthcare. **Full text:** https://goo.gl/WBcVnw

Cremation and Christianity: English Anglican and Roman Catholic attitudes to cremation since 1885

MORTALITY | Online – 17 November 2017 – Britain was the first modern European country to adopt the widespread practice of cremation, and by 2010, it took place in around three-quarters of all funerals. Although the clergy had ceased to be the exclusive custodians of funeral ritual, their views and example remained highly significant in conveying approval, or disapproval, of cremation to their religious constituencies. This article explores attitudes to cremation amongst the English Anglican and Roman Catholic leadership in the twentieth century. In the first half of the century, a number of high-profile Anglican bishops promoted cremation by both teaching and example. The Roman Catholic Church, however, remained opposed to the practice, which it equated with atheism and inhumanity. Although the Catholic position began to soften from the 1960s, it is evident that some reticence about cremation remains. The different approaches to cremation illuminate a subtle religious and cultural fault line between the two ecclesial communities which has hitherto been little explored. **Abstract:** https://goo.gl/YotUj4

Noted in Media Watch 27 August 2012 (#268, p.3):

- U.S. (Florida) | *The Sun-Sentinel* (Fort Lauderdale) – 19 August 2012 – '**Jews wrestle with cremation vs. traditional burial.**' A relative demands to be cremated, contrary to Jewish law, while the family wants a traditional Jewish burial. What to tell the family? Jewish leaders say the precedent is clear: Dead bodies should be buried, as Abraham buried his wife Sarah in the biblical Book of Genesis. Still, rabbis say they understand the burden. https://goo.gl/vuJGLk

N.B. Additional articles on the VOICES (SF) questionnaire are noted in the 4 September 2017 issue of Media Watch (#528, p.8).

End-of-life care in Northern Ireland

Insights into the factors associated with achieving the preference of home death in terminal cancer: A national population-based study

PALLIATIVE & SUPPORTIVE CARE | Online – 23 November 2017 – Some 467 of 1,493 invited informants completed a survey. The 362 who expressed a preference for dying at home and spent time at home in their final 3 months were included in the authors' analysis. Of these, 53.4% achieved their preference of a home death. Factors positively associated with achieving a home death were: 1) Living in an affluent area; 2) Receipt of good and satisfactory district nurse care; 3) Discussing place of death with health professionals; and 4) The caregiver's preference for a home death. Being older than 80 years of age, being a Presbyterian, and being unconscious most of the time during their final week were negatively associated with achieving a home death. Communication, care satisfaction, and caregiver preferences were all associated with home death.. **Abstract:** https://goo.gl/7tLEvd

ipcrc.net

The International Palliative Care Resource Center expired on 10 November 2017 and is pending renewal.

End-of-life debate in France

Citizen's point of view about deep and continuous sedation

LA REVUE DE MÉDECINE INTERNET | Online – 1 November 2017 – Sedation in palliative care (PC) meets a precise definition and corresponds to a medical practice. In 2015, citizen expressed their views on the Claeys-Leonetti bill by means of a consultative forum made available on the Internet site of the National Assembly. Among the 1,819 Internet users who participated in the forum, 67 expressed their views as health professionals, 25 of whom were directly involved in PC, as well as 10 sick persons. Analysis ... highlighted two classes of statements. The first dealing with deep and continuous sedation, reflecting the specificity of the discourse of the Internet users. The second one consisted of textual units in which the modal verbs were dominant and overrepresented, thus providing information on the participants' perceptions. The thematic analysis highlighted four themes: 1) Death; 2) Intent; 3) Treatment; and, 4) Fear. Deep and continuous sedation is perceived as a euthanasic practice or raises fear of such a drift. Provision of extended and accurate information to the population and health professionals is essential to ensure that this new model of sedation is integrated into the care of the terminally ill patients and their families. **Abstract:** https://goo.gl/kxrjbb

N.B. French language article.

Noted in Media Watch 23 January 2017 (#496, p.6):

- *BMC PALLIATIVE CARE* | Online – 21 January 2017 – **'Opinions about the new law on end-of-life issues in a sample of French patients receiving palliative care.'** In February 2016, the French government enacted the Claeys-Leonetti law that forbade euthanasia and established the right to deep and continuous sedation for end-of-life patients. Moreover, the law also obliges clinicians to abide by any advance directives (ADs) regarding treatment and investigation, except in cases where they are "obviously inappropriate" in a given medical situation, or in cases of emergency, in order to allow medical staff to take time to assess the patient's situation. Artificial feeding and hydration are considered as treatment. **Full text:** https://goo.gl/u8J853

N.B. Selected articles on continuous sedation, including international variations in clinical practice guidelines, are noted in the 17 July 2017 issue of Media Watch (#521, p.16).

CSPCP Canadian Society of Palliative Care Physicians
SCMSP Société canadienne des médecins de soins palliatifs

Continuous palliative sedation therapy

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS | Online – 4 November 2017 – Con-tinuous palliative sedation therapy (CPST) is receiving increasing attention as it is often being offered as an alternative to medically assistance in dying (i.e., MAiD). This means that more physicians may be considering using the treatment – without necessarily being familiar/competent to use it. The Society strongly recommends that all physicians create or adopt a specific policy on CPST for their practice group or institution. This will ensure CPST is a transparent practice that is easily distinguished from practices that hasten death and are subject to best practice. The Society's statement to this effect includes links to sample policies. **Download/view statement at:** https://goo.gl/gza6Lm

N.B. 'Framework for Continuous Palliative Sedation Therapy in Canada,' Canadian Society of Palliative Care Physicians. **Download/view at:** https://goo.gl/oiDeTu

Adaptation and validation of the VOICES (Short Form) questionnaire for evaluation of end-of-life care in Sweden

SCANDINAVIAN JOURNAL OF PUBLIC HEALTH | Online – 17 November 2017 – Instruments for evaluating end-of-life care (EoLC) by voicing experiences of family members have previously been lacking in Sweden. The objective of this study was therefore to adapt and validate the VOICES (SF) questionnaire

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to evaluate quality of EoLC in Sweden. The VOICES (SF) – Views of Informal Carers – Evaluation of Services (Short form) – is a questionnaire about bereaved relatives' experiences of care in the last three months of life of a deceased family member. The main concerns emerging from the content validation related to the understanding and clarity of some of the questionnaire items, and a few concerns regarding the relevance of different response alternatives or items. Only two of the family members found it emotional to complete the questionnaire, and they still deemed completing it to be important and manageable. The VOICES (SF) can be considered as feasible in the Swedish context, provided that cultural adaptation has been achieved, that is translation alone is not enough. **Abstract:** https://goo.gl/MtTzfU

Noted in Media Watch 6 November 2017 (#537, p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 3 November 2017 – **'Developing the methods and questionnaire for a national retrospective mortality follow-back survey of palliative and end-of-life care in England.'** The National Survey of Bereaved People was conducted by the Office for National Statistics ... for the first time in 2011, and repeated annually thereafter. It is thought to be the first time that nationally representative data have been collected annually on the experiences of all people who have died, regardless of cause and setting, and made publicly available informing palliative and end-of-life policy, service provision and development, and practice. This paper describes the development of the questionnaire used in the survey (VOICES-SF), a short-form of the VOICES (Views Of Informal Carers – Evaluation of Services) questionnaire, adapted specifically to address the aims of the national survey. **Abstract:** https://goo.gl/Ncjj7A

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *HEALTH AFFAIRS* | Online – 20 November 2017 – **'Accepting professional accountability: A call for uniform national data collection on medical aid in dying.'** Those on both sides of the debate over legalizing aid-in-dying have raised important concerns as the practice has spread. For example, opponents worry about mistakes in implementation, vulnerable individuals being coerced into an assisted death, and a slippery slope leading to patients being killed against their will. Meanwhile, supporters worry about insurance coverage for increasingly expensive aid-in-dying medications and about other possible drivers of inequitable access by race, ethnicity, geography, disability, and other factors. Both opponents and supporters are concerned about safe disposal of unused medications and medical complications that can arise during the process. **Full text:** https://goo.gl/KZmTjV

Journal Watch

Federal Trade Commission halts the deceptive practices of academic journal publishers

U.S. | Federal Trade Commission (Washington DC) – 22 November 2017 – A federal court has granted a preliminary injunction requested by the Commission, temporarily halting the deceptive practices of academic journal publishers charged by the agency with making false claims about their journals and academic conferences, and hiding their publishing fees, which were up to several thousand dollars. The preliminary injunction against OMICS Group Inc., iMedPub LLC, Conference Series LLC stems from a complaint the Commission filed last year. According to the complaint, the defendants deceptively claim that their journals provide authors with rigorous peer review and have editorial boards made up of prominent academics when in fact, many articles are published with little to no peer review and many individuals represented to be editors have not agreed to be affiliated with the journals. https://goo.gl/RSTMGB

N.B. See Retraction Watch: https://goo.gl/XrocPi

The OMICS Group of publications include the *Journal of Palliative Care & Medicine*: http://goo.gl/ieTbLZ.

Cont.

Noted in Media Watch 5 December 2016 (#490, p.2):

- CANADA | *The Ottawa Citizen* – 28 November 2016 – **'Shadowy publisher of Canadian medical journals retracts "steaming pile of dung"'** The *Citizen* exposed scientific fraud by the new owners of two Canadian medical publishing firms – printing fake research for cash. Now, after the news got international publicity, the company that published our trashy little fake study is retracting it. OMICS International, based in India, bought Pulsus Group and Andrew John Publishing this year. Both were reputable medical journal publishers, but under OMICS they have been used as fronts for "predatory" publishing. https://goo.gl/9n3CoI

What should we do about predatory publishing?

EUROPEAN SCIENCE EDITING, 2017;43(4):80-82. "Predatory" publishing covers a wide range of journals with different characteristics. Society and scientists should not accept deceitful practices in science. Neither should we accept anything less than excellence from publishing houses. Therefore, we should take three measures: first, form committees for each research field to keep track of journals and publishers; second, create a forum where scientists can share their experiences of predatory journals; third, develop software to help scientists and officials spot references to predatory journals in papers and in applications for funding, promotions, or positions. **Abstract:** https://goo.gl/8mNJqi

A call for clarity and quality in medical writing

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2017;189(46):e1407. Words matter in science that matters. Far too often, however, the words in medical literature are chosen and arranged without enough care. This leads to confusing, jargon-filled writing that is difficult to read, even for medical researchers. Not only is careless writing a barrier to publication, it makes it more difficult for peers to understand and build on other researchers' work. Poor communication limits the impact of medical research, so clinicians and patients ultimately suffer as well. Vague and ambiguous clinical practice guidelines, for example, have been linked to medical errors and inconsistent interpretation. Writing about complex medical research in plain language is challenging. Technical terms, acronyms and jargon, although used too frequently, cannot be avoided entirely. But the benefits – improved knowledge translation, less research waste – are too great for needlessly complicated writing to be accepted as inevitable. Medical educators, academic institutions and health care researchers have a duty to improve the quality of written communication to extend the reach of useful medical knowledge. Poor writing has always been a problem in medicine. A century-old editorial in this journal suggested there is "probably more bad writing in medical journals than in any other kind of periodical."[1] Five decades later, the problem remained. Quality in scientific writing "seems to have no value in a marketplace that prizes the commonplace and accepts the shoddy," lamented a Canadian researcher in 1964.[2] **Full text:** https://goo.gl/1EL9Ri

1. 'Style in medical writing,' *Canadian Medical Association Journal*, 1911;1(1):70-73. **Access options:** https://goo.gl/oZTszM

2. 'Quality in scientific writing,' *Canadian Medical Association Journal*, 1964;90(19):1121-1125. **Access options:** https://goo.gl/xKFc5Z

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Media Watch: Online

International

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

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

www.ipcrc.net expired on 11 November 2017 and is pending renewal

Cont.

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

PALLIMED: http://goo.gl/7mrgMQ
[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole']

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: https://goo.gl/psUfub
[Scroll down to 'Resource Collection']

SINGAPORE | Centre for Biomedical Ethics (CENTRES): https://goo.gl/UZTPVU
Listing of resources in the process of being update

Canada

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: https://goo.gl/BLgxy2
[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): https://goo.gl/wGi7BD
[Scroll down to 'Additional Resources']

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

ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYC
[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: https://goo.gl/LsTFXU
[Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Magyar Hospice Alapítvány: https://goo.gl/ygkX45

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

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