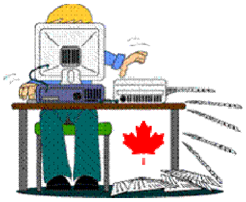
Media Watch...

*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.*

6 August 2018 Edition | Issue #575



Compiled & Annotated by Barry R. Ashpole

Informing best practice: Scroll down to Specialist Publications and 'The role of the healthcare chaplain: A literature review' (p.12), in *Journal of Health Care Chaplaincy*.

Canada

British Columbia seniors at privately run care homes more likely to die in hospital: Report

BRITISH COLUMBIA | *The Vancouver Sun* – 1 August 2018 – The province's seniors advocate has ignited a fiery debate over the types of elder care facilities in British Columbia (BC), with a new report that says seniors who live in privately run care homes are far more likely to die in hospital than those who live publicly run care homes. The report[1] ... said a senior in a facility run by a private company, a non-profit or a religious organization was 32% more likely to be sent to their local emergency department and 54% more likely to die while there. The seniors advocate, Isobel Mackenzie, called the discrepancy "stunning" and wrote that private operators appear to be persistently failing compared to publicly run facilities when it comes to keeping seniors out of hospital emergency rooms, where their health is threatened by stress, a lack of mobility and hospital-acquired infections. Reducing the hospitalization rates could save the province's health system $16 million a year, free up 15,481 beds and fund half a million additional care hours per year, she estimated. Almost 28,000 seniors in BC live in 293 publicly subsidized facilities. Roughly one-third of beds are operated by a public health authority. The rest are run by contractors (including both private companies, non-profits and religious organizations) who receive funding from the government. https://goo.gl/pueZc3

Specialist Publications

'Home palliative service utilization and care trajectory among Ontario residents dying on chronic dialysis' (p.10), in *Canadian Journal of Kidney Health & Disease*.

'Medical assistance in dying: Implications for Canadian classrooms...' (p.16), in *Interchange*.

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1. 'From Residential Care to Hospital: An Emerging Pattern,' Office of the Seniors Advocate BC, August 2018. **Download/view at:** https://goo.gl/FztK39

N.B. No mention is made in the Office of the Seniors Advocate report of palliative or end-of-life care. A January 2017 report by the BC Care Providers Association, noted in the 30 January 2017 issue of Media Watch (#497, p.1), recommended that the provincial government "support the adoption of new palliative/end-of-life care (EoLC) models and, where necessary, provide new funding to improve the integration between continuing and EoLC"; download/view 'Strengthening Seniors Care: A Made-in-BC Roadmap' at: https://goo.gl/z4iTBG.

Canadians with terminal illness getting new fast-track test for Canadian Pension Plan disability benefits

THE CANADIAN PRESS | Online – 31 July 2018 – The federal government will set a new test for fast-tracking disability pension requests from Canadians with terminal illnesses. The $4.3 billion Canada Pension Plan disability program fast-tracks benefits decisions for dying Canadians, but has faced hurdles in meeting the processing timelines. The government plans to change the rules to grant an expedited review to people whose doctors believe have just six months left to live. Documents under the access to information law show the decision to rewrite the policy is aimed at untangling problems in how the government decides who deserved a speedy decision. A briefing note earlier this year to senior officials in Employment & Social Development Canada notes the department's definition of terminal illness was problematic enough that it may have clogged up the fast-track system. Auditor general Michael Ferguson's February 2016 review of the disability pension program found people with terminal or grave conditions were waiting too long for benefits or being snowed under by complicated paperwork. https://goo.gl/wv7MZn

Noted in Media Watch 8 February 2016 (#448, p.1):

- CTV NEWS | Online – 2 February 2016 – **'Terminally-ill Canadians wait too long for disability pensions.'** Canadians with terminal illnesses are waiting too long for disability pension benefits from the federal government, and those with grave conditions are being snowed under with paperwork, Canada's auditor general says.[1] While the audit found no documented cases of patients dying while waiting for benefits, it did find that guidelines for decisions weren't always being met. http://goo.gl/sVOR8R

  1. 'Report 6: Canada Pension Plan Disability Program,' Auditor General of Canada, February 2016. **Download/view at:** http://goo.gl/zGtcaO

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *The Calgary Herald* – 3 August 2018 – 'Alberta doctor-assisted deaths up nearly 50% this year.' Until the end of July, there were 172 of the deaths in the province, putting Alberta on pace to record about 300 of the procedures that were first conducted in Canada in 2016. In 2017, there was a total of 205 and since 2016 at least 440 Albertans have died with the assistance of physicians. It's difficult to pinpoint a reason for the increased numbers, but it's a pattern seen in other places that legally allow such procedures to end the suffering of those who consent to it, said Dr. Jim Silvius, who oversees Alberta's program. Silvius said the number of physician-assisted deaths in Alberta remains a tiny portion of overall mortality and that safeguards outlining a requirement that those seeking it must already be facing a "reasonably foreseeable" death remain. https://goo.gl/xmjKkR

U.S.A.

As America's incarcerated age, the need for hospice rises

THE JOHN A. HARTFORD FOUNDATION | Next Avenue (St. Paul, Minneapolis) – 3 August 2018 – At the Louisiana State Penitentiary prison known as Angola, over 80% of the 6,500 inmates are serving life sentences and can expect to die behind bars. Of those who eventually receive terminal medical diagnoses, many voluntarily choose to enter Angola's innovative hospice program in lieu of pursuing medical care. Hospice care programs like the one at Angola have opened across the country in prison facilities desperate for ways to meet the needs of their increasingly aging incarcerated populations. As this demographic trend continues, some proponents of humane end-of-life care in prisons are advocating for even more wardens to implement hospice programs, while others work to increase the number of "compassionate releases" granted to inmates. https://goo.gl/75UNtn

N.B. 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 (last updated 1 August 2018) is available on request. Contact information at the foot of p.19.

Bill would grant 12 weeks' paid bereavement leave to all New York workers

NEW YORK | *The New York Post* – 1 August 2018 – A new mandatory bereavement pay bill is awaiting Governor Cuomo's signature – and it would give every employee in the state 12 weeks of paid time off if they suffer a death in the family. The legislation, which quietly passed the Senate and Assembly in the waning days of the legislative session, would be an addition to the state's Paid Family Leave law, which went into effect in January. The bereavement provision would cover the death of a worker's spouse or domestic partner, child, parent, parent-in-law, grandparent or grandchild. Under the Paid Family Leave law, workers can collect a portion of their average weekly wage – ranging from 50 to 67% as the law is phased in – but capped at the corresponding amount of the state-wide average. The state average weekly wage is currently $1,357, according to the Department of Labor, which means the most anyone can currently collect is about $680 a week. The law guarantees a worker the same or comparable job when they return from leave, and bars employers from cutting off health insurance. https://goo.gl/wjP8oY

Specialist Publications

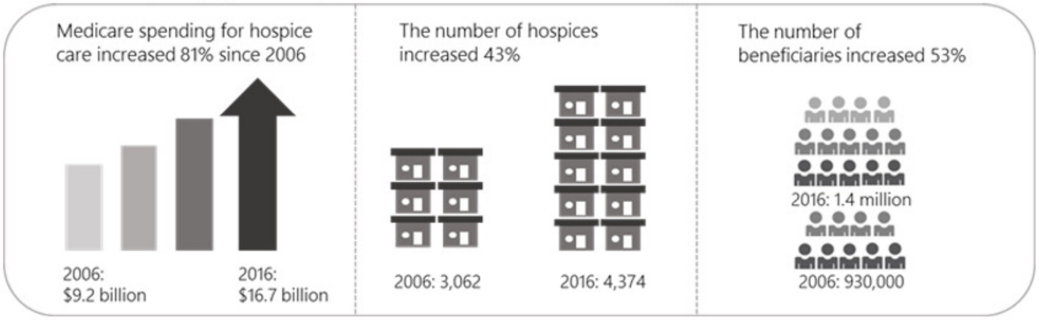
'Public awareness and perceptions of palliative and comfort care' (p.8), in *American Journal of Medicine*.

'Roles of physicians in healthy dying' (p.9), in a special issue of *American Medical Journal of Ethics* focusing on on end-of-life care.

Missed visits, uncontrolled pain and fraud: Report says hospice lacks oversight

WASHINGTON DC | *Kaiser Health News* – 31 July 2018 – Elderly patients spent over two weeks in uncontrolled pain or respiratory distress. Acute care was rare on weekends. And recruiters went door to door pitching fraudulent schemes, luring healthy patients to sign up for hospice in exchange for free housecleaning and medicine. These details appear in a report on hospice released by a government watchdog agency calling on federal regulators to ramp up oversight of a booming industry that served 1.4 million Americans in 2016. The report from the Office of Inspector General (OIG) at the Department of Health & Human Services sums up over 10 years of research into inadequate care, inappropriate billing and outright fraud by hospices, which took in $16.7 billion in Medicare payments in 2016.[1] A *Kaiser Health News* investigation last year revealed that while many of the nation's 4,000-plus hospices earn high satisfaction rates on family surveys, hundreds fell short of their obligations, abandoning families at the brink of death or skipping other services they had pledged to provide.[2] The OIG report points to similar gaps in care and raises concerns that some hospices are milking the system by skimping on services while taking in daily Medicare payments. Regardless of how often their staff members visit, hospices collect the same daily flat rate from Medicare for each patient receiving routine care: $193 for the first 60 days, then $151 thereafter, with geographic adjustments as well as extra payments in a patient's last week of life. The report calls on the Centers for Medicare & Medicaid Services to take 15 actions to improve oversight, including tying payment to quality of care and publishing public inspection reports on its consumer-focused website, Hospice Compare, as it does for nursing homes. https://goo.gl/4XrfsB

Exhibit 1: Hospice payments, providers, and beneficiaries have grown.



Source: OIG analysis of CMS data, 2017.

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1. ‘Vulnerabilities in the Medicare Hospice Program Affect Quality Care and Program Integrity: An OIG Portfolio,’ Office of Inspector General, U.S. Department of Health & Human Services, July 2018. **Download/view at:** https://goo.gl/DPTmw9

2. ‘“No one is coming”: Investigation reveals hospices abandon patients at death’s door,’ *Kaiser Health News*, published online 26 October 2017. [Noted in the 30 October 2017 issue of Media Watch (#536, pp.4-5)] https://goo.gl/a4TtDp

N.B. Additional articles on the hospice “market” in the U.S. noted in the 9 July 2018 issue of Media Watch (#571, pp.3-4). National Hospice & Palliative Care Organization response to the Office of Inspector General’s report: https://goo.gl/Q7ijUi

Assisted suicide is controversial, but palliative sedation is legal and offers peace

THE WASHINGTON POST | Online – 30 July 2018 – While aid-in-dying, or “death with dignity,” is legal in seven states and the District, medically assisted suicide retains tough opposition. Palliative sedation (PS), though, has been administered since the hospice care movement began in the 1960s and is legal everywhere. Doctors in Catholic hospitals practice PS even though the Catholic Church opposes aid-in-dying. According to the U.S. Conference of Catholic Bishops, the church believes that “patients should be kept as free of pain as possible so that they may die comfortably and with dignity.” Because there are no laws barring PS, the dilemma facing doctors who use it is moral rather than legal, said Timothy Quill, who teaches psychiatry, bioethics and palliative care (PC) medicine at the University of Rochester Medical Center in New York. Some doctors are hesitant about using it “because it brings them right up to the edge of euthanasia,” Quill said. But Quill believes that any doctor who treats terminally ill patients has an obligation to consider PS. “If you are going to practice PC, you have to practice some sedation because of the overwhelming physical suffering of some patients under your charge.” Doctors wrestle with what constitutes unbearable suffering, and at what point PS is appropriate – if ever. Policies vary from one hospital to another, one hospice to another, and one PC practice to another. https://goo.gl/t8s8ez

Noted in Media Watch 9 July 2018 (#571, p.16):

- *THEORETICAL MEDICINE & BIOETHICS* | Online – 2 July 2018 – **‘Sedation and care at the end of life.’** Christianity affirms a duty to relieve unnecessary suffering yet also proscribes euthanasia. Accordingly, the question arises as to whether it is ever morally permissible to render dying patients unconscious in order to relieve their suffering. If so, under what conditions? Is this practice genuinely morally distinguishable from euthanasia? Can one ever aim directly at making a dying person unconscious, or is it only permissible to tolerate unconsciousness as an unintended side effect of treating specific symptoms? What role does the rule of double effect play in making such decisions? Does spiritual or psychological suffering ever justify sedation to unconsciousness? What are the theological and spiritual aspects of such care? **Abstract (inc. list of references):** https://goo.gl/wE4iiz

N.B. Selected articles on palliative sedation noted in the 23 April 2018 issue of Media Watch (#560, p.15).

Hospice said to be underutilized

ARKANSAS | *Northwest Arkansas Democrat-Gazette* (Little Rock) – 29 July 2018 – Northwest Arkansas has four Medicare-approved agencies with offices in Washington or Benton counties... Despite a growth in awareness and resources, many eligible patients aren’t taking full advantage of hospice benefits, said Catherine Grubbs, of Circle of Life Hospice. Terminally ill patients often suffer longer under intensive curative treatments when they resist transitioning to comfort care. A state report indicated Washington and Benton counties need more hospice beds to meet the projected need of patients this year, but Northwest Arkansas providers say they have never turned a patient away because of a lack of resources. Medicare or Medicaid pays for qualifying patients’ hospice care related to their terminal illness for six months or as long as a doctor certifies they are terminally ill... Arkansas Hospice, Circle of Life and Washington Regional Hospice provide financial support for patients who cannot pay for necessary care... More than half of Medicare hospice patients in 2016 were enrolled for 30 days or less... Arkansas patients using Medicare benefits spent less time in hospice care on average than others around the country... https://goo.gl/oRMxf7

International

When doctors and caregivers do not help patients make the best decisions

SINGAPORE | *Today* (Singapore) – 31 July 2018 – The doctor patient relationship in Singapore is changing. In decades past, it was typically the doctor who made treatment decisions on behalf of patients, sometimes with input from the patients and/or their families, and sometimes without any input at all. Now, partly due to the threat of litigation, shared decision-making is increasingly the norm. Shared decision-making involves information sharing between doctors and patients and/or the patient's designated surrogates in efforts to come up with an appropriate treatment plan. This sounds like the ideal strategy for how medical decisions should be made. However, shared decision-making inherently assumes that patients are capable of taking in complex information from healthcare providers, often at a most vulnerable time in their lives, and then synthesising that information to make rational treatment choices. It also assumes that their family caregivers, who are major influencers in healthcare decisions, are acting in the best interests of the patient. There is both theoretical and empirical evidence suggesting that these assumptions are unlikely to hold, and the consequence is likely over-treatment, sometimes with high cost and only marginally effective medical care. https://goo.gl/vb9htY

Specialist Publications

'Palliative care: The need of the modern era' (p.10), in *Hong Kong Medical Journal*.

'Variation in out-of-hospital death among palliative care inpatients across public hospitals in New South Wales, Australia' (p.11), in *Internal Medicine Journal*.

'Place of death in centenarians in Taiwan and the need for home hospice care' (p.15), in *Taipei City Medical Journal*.

'Public support for the right to euthanasia: Impact of traditional religiosity and autonomy values across 37 nations' (p.17), in *International Journal of Comparative Sociology*.

How the Internet is changing the way we grieve

U.K. | The Conversation – 31 July 2018 – People don't die in the same way that they used to. In the past, a relative, friend, partner would pass away, and in time, all that would be left would be memories and a collection of photographs. These days the dead are now forever present online and digital encounters with someone who has passed away are becoming a common experience. Each one of us has a digital footprint – the accumulation of our online activity that chronicles a life lived online through blogs, pictures, games, web sites, networks, shared stories and experiences. When a person dies, their "virtual selves" remain out there for people to see and interact with. These virtual selves exist in the same online spaces that many people use every day. And this is a new and unfamiliar phenomenon that some people might find troubling – previously dead people were not present in this way. Yet for some, these spaces have become a valuable tool – especially so for the bereaved. An emerging body of research is now looking at the ways the internet, including social media and memorial websites, are enabling new ways of grieving – that transcend traditional notions of "letting go" and "moving on." https://goo.gl/u8ij3H

Noted in Media Watch 5 February 2018 (#549, p.15):

- *SOCIAL MEDIA & SOCIETY* | Online – 25 January 2018 – **'Do not click "like" when somebody has died: The role of norms for mourning practices in social media.'** Social media constitute new social spaces where the topics of death, loss and mourning are increasingly encountered and negotiated. Users might either engage in mourning practices themselves or be confronted with other users' mourning during their everyday social media use. The omnipresence of mourning in social media poses challenges to the users and increases the need for norms... **Full text:** https://goo.gl/Y1vkwa

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Noted in Media Watch 8 May 2017 (#511, p.14):

- *MORTALITY* | Online – 2 May 2017 – **'Mourning and memory in the twittersphere.'** Emerging work in the field of social media and mourning suggests that social media spaces have changed the landscape of grief by encouraging mourners to form communities online, post public statements about loss, and maintain continuing bonds with the deceased. While existing studies restrict their analyses to public or private online spaces. The authors examine a space that is suited to both private communication and information broadcast. **Abstract (w. link to references):** https://goo.gl/emsYyn

Noted in Media Watch 13 June 2016 (#466, p.4):

- U.S. | *The Atlantic* – 8 June 2016 – **'The space between mourning and grief.'** Some argue that the likes of Facebook and Twitter have opened up public space for displays of grief that had been restricted to private spheres of secular culture. But rather than reconstructing an outlet for public grief, social media often reproduces the worst cultural failings surrounding death, namely platitudes that help those on the periphery of a tragedy rationalize what has happened, but obscure the uncomfortable, messy reality of loss. http://goo.gl/VMUX9p

Dying young in Stockton – England's most unequal town

U.K. (England) | BBC News (London) – 30 July 2018 – The life expectancy gap between rich and poor people in England has been widening for nearly two decades. The rich stay healthy longer. The poor die younger. That bleak assessment is based on national data. Stockton-on-Tees is the town with England's biggest gap in life expectancy, according to Public Health England.[1] In Stockton-on-Tees, those living in the wealthier areas can expect to live as much as 18 years longer than those in the more deprived parts of the town. It reflects a national problem. Nationally, on average, a boy born in one of the most affluent areas of England will outlive one born in one of the poorest parts by 8.4 years. In the centre of Stockton life expectancy for a man is 64. That's the same as Ethiopia. The reasons for the health inequality gap are complicated. Professor Clare Bambra, from Newcastle University, led a five-year study into health inequality in Stockton.[2] https://goo.gl/HuopEx

1. 'Health state life expectancies by national deprivation deciles, England & Wales: 2014 to 2016,' Office for National Statistics. **Download/view at:** https://goo.gl/72GnTx

2. 'Local Health Inequalities in an Age of Austerity: The Stockton-on-Tees Study (2013-2018),' Institute of Health & Society, University of Newcastle. **Project details at:** https://goo.gl/6qXDjp

Noted in Media Watch 20 March 2017 (#504, p.4):

- U.K. (England) | *The Darlington & Stockton Times* – 16 March 2017 – **'Council investigates end-of-life care in North Yorkshire.'** North Yorkshire County Council's scrutiny of health committee has drawn up a report highlighting the need for investment into a multi-agency, community-based provision for people in the final months of their lives, after it conducted a six month investigation into end-of-life care (EoLC) in the county. The report highlights that while the majority of people experience good quality EoLC 25% do not. It also found that while most people would prefer to die in their own home, 43% die in hospital, with all the associated, significant costs. https://goo.gl/poIIKd

Supreme Court backs agreed end-of-life decisions

U.K. (England, Northern Ireland, Scotland & Wales) | BBC News (London) – 30 July 2018 – Legal permission will no longer be required to end care for patients in a long-term permanent vegetative state, the Supreme Court has ruled.[1] It will now be easier to withdraw food and liquid to allow such patients to die. When families and doctors are in agreement, medical staff will be able to remove feeding tubes without applying to the Court of Protection. [Justice] Lady Black ruled there was no violation under the Human Rights Convention. The Court of Protection has ruled on cases for 25 years, but the process can take months or years, and it costs health authorities about £50,000 in legal fees to lodge an appeal. The ruling

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could have an impact on the thousands of families whose loved ones are in a vegetative state. It is estimated about 24,000 people in the U.K. are in a persistent vegetative state or a minimally conscious state. In the Supreme Court judgement, Lady Black said an agreement between families and doctors was sufficient safeguarding to ensure "public confidence." But she urged families to apply to court "where there are differences of view" between relatives or medical professionals. https://goo.gl/9hJEzs

1. 'An NHS Trust and others (Respondents) v Y (by his litigation friend, the Official Solicitor) and another (Appellant),' The Supreme Court, 30 July 2018. **Download/view at:** https://goo.gl/97i4Ve

Noted in Media Watch 26 May 2018 (#556, p.14):

- *PALLIATIVE MEDICINE* | Online – 23 March 2018 – **'Deaths after feeding-tube withdrawal from patients in vegetative and minimally conscious states: A qualitative study of family experience.'** Interviewees were usually anxious in advance about the nature of the death and had sometimes confronted resistance from, and been provided with misinformation by, healthcare staff in long-term care settings. However, they overwhelmingly described deaths as peaceful and sometimes even as a "good death." There was (for some) a significant "burden of witness" associated with the length of time it took the person to die and/or distressing changes in their appearance. **Abstracts:** https://goo.gl/sxQHAa

Noted in Media Watch 2 January 2017 (#493, p.4):

- U.K. (England, Northern Ireland, Scotland, & Wales) | BBC News (London) – 21 December 2016 – **'How many minimally conscious patients are there in the U.K.?'** The National Health Service (NHS) does not publish data on these patients. The BBC requested information from all Clinical Commissioning Groups and NHS bodies across the U.K. The responses showed more than 100 people with prolonged disorders of consciousness are currently being cared for by the NHS. Many of the 105 patients have been in this state for more than six months. The data comes from a BBC Freedom of Information enquiry, but gives an incomplete picture, as only a quarter of all bodies responded. https://goo.gl/qopcc1

N.B. Selected articles on judicial approaches to "the (non-) treatment of minimally conscious patients" noted in the 24 April 2017 issue of Media Watch (#509, p.13).

Hospice course helps primary pupils explore life and death

U.K. (England) | *The Worthing Herald* – 29 July 2018 – Primary school pupils are involved in a pioneering project enabling them to learn about hospice care. Children aged nine and ten are taken on several visits to St. Barnabas House in Worthing, where they are paired with a patient to get to know each other and take part in activities together. The project explores concepts of life, death, dying and bereavement, introducing the children to hospice care in a safe and non-threatening environment. Project lead Marcelle Palmer said: "Across the whole of West Sussex, approximately 2,830 schoolchildren aged five to 16 have been bereaved of a parent or sibling. One aim of the project is that children, parents and teachers feel better informed and more comfortable talking about death and dying. Children, parents and teachers will also have a better understanding of St. Barnabas House and hospice care, while patients have reported improvements in wellbeing and reduced feelings of social isolation." Visits are made once a week for the three-week course and the children are encouraged to ask patients questions about their illnesses and experiences, with support and guidance from hospice staff. https://goo.gl/e2R9DK

Noted in Media Watch 9 July 2018 (#571, p.5):

- AUSTRALIA (Queensland) | BBC News (London, England) – 4 July 2018 – **'Putting death on the school timetable.'** Maths, science, history and death? This could be a school timetable in a state in Australia, if a proposal by the Australian Medical Association Queensland is accepted. They want young people to be made more familiar with talking about the end of life. Doctors say that improvements in medicine and an ageing population mean that there are rising numbers of families facing difficult questions about their elderly relatives and how they will face their last days. But too often young people in the West are not prepared for talking about such difficult decisions. https://goo.gl/sLkPh1

N.B. Additional articles on initiatives to educate young people about palliative and end-of-life care noted in this issue of Media Watch.

Specialist Publications

Might rebranding palliative care improve its integration into treatment for those patients diagnosed with pulmonary arterial hypertension?

ADVANCES IN PULMONARY HYPERTENSION, 2018;17(1):34-35. While improved education of patients and the general public is non-controversial, a reasonable consideration related to patients with pulmonary arterial hypertension is whether rebranding palliative care may be an underappreciated yet effective measure for increasing early access to palliative care in the near term. To address this main question, the author examines several sub-questions: 1) Is the term “palliative care” opaque and/or associated with negative connotations by physicians, patients, and their families; 2) Is there evidence that an alternative term, such as “supportive care,” may be viewed more favorably; and 3) Has rebranding using “supportive care” been adopted by medical centers with improved outcomes? **Full text:** https://goo.gl/mWFpSC

> **N.B.** The focus of the current issue of *Advances in Pulmonary Hypertension* is palliative care. **Contents page:** https://goo.gl/AxyTAh

Noted in Media Watch 23 April 2018 (#560, p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 20 April 2018 – **‘Increasing information dissemination in cancer communication: Effects of using “palliative,” “supportive,” or “hospice” care terminology.’** When attempting to share information about comfort-oriented care, many use “palliative,” “supportive,” and “hospice” care terminology interchangeably, but we lack evidence about the effects of using these different terms. In this study, the terminology used had a large effect and, compared with alternatives, the information labeled as being about “supportive” care was significantly more likely to be selected. **Abstract:** https://goo.gl/1mWwno

Public awareness and perceptions of palliative and comfort care

AMERICAN JOURNAL OF MEDICINE | Online – 2 August 2018 – Palliative care (PC) aims to improve quality of life for patients and their caregivers by addressing the physical, psychosocial and spiritual challenges of facing life-limiting illness and evidence is mounting that it is effective in doing so. However, palliative services are underutilized nationally in part due to a shortage of board-certified PC providers. This problem is compounded by the public’s general lack of awareness regarding these services as evidenced by the public curiosity near the end of Mrs. [Barbara] Bush’s life. The proportion of Americans aged 65 and older is projected to increase from 46 million to over 98 million by 2060. This increase will bring with it an unprecedented prevalence of chronic and end-stage illnesses and thereby a greater need for practitioners who are skilled in providing PC for those patients and their families. Strategies aimed at increasing the provision of PC should focus on raising awareness and addressing misperceptions among the public and re-aligning educational and incentive-based policies to ensure that the U.S. healthcare system can provide high-quality care for patients throughout all stages of life. **Full text:** https://goo.gl/GySVyc

Noted in Media Watch 30 April 2018 (#561, p.3):

- U.S. (Pennsylvania) | *The Inquirer* (Philadelphia) – 24 April 2018 – **‘Barbara Bush and the problem with “comfort care.”‘** Scouring Twitter after the announcement, I found that most tweets expressed sorrow, largely because Mrs. Bush was electing comfort care and that meant that she would die imminently. Many other tweets lauded her choice of comfort care, noting how brave she was to stop treating her illness. Both of these sentiments reflect the language problem that doctors and patients have at the end of life. When physicians such as me divide care into “medical treatment” and “comfort care,” we ignore that we should focus on both comfort and medical treatment at the same time. Medicare policy reinforces the divide between medical care and comfort care. https://goo.gl/B6SKbE

Ethical dimensions of caring well for dying patients

AMERICAN MEDICAL JOURNAL OF ETHICS, 2018;20(8):E678-682. Dying is a uniquely individual yet deeply shared and universal experience; it profoundly impacts perceptions of culture, personhood, and identity. For many Americans, it is also an experience widely discrepant from the one they want and envision for themselves and their loved ones. Over the past decade, there has been growing awareness of the incongruence between the way Americans say they want to die and how they actually do. But while most would agree that this reality is not the ideal that clinicians or patients strive for, what is less agreed upon is what the roles of clinicians and patients should be in defining what actually constitutes dying and good care of dying people. What do patients and clinicians need to know about dying and care at the end of life (EoL)? What barriers exist to accessing and employing this knowledge in the face of difficult decisions? To best answer these questions, it is useful to examine the social structures and supports already in place for EoL care and to understand how they are being utilized. To begin with, hospital palliative care (PC) programs are expanding rapidly in order to meet the physical and emotional needs of patients with serious or terminal illness. Robust evidence now exists demonstrating that early PC improves the dying experience for both patients and families while generally reducing health care costs and potentially prolonging survival. Despite these facts, there is significant variation in physician practice in the care of patients at the EoL and a general consensus that palliative and hospice care are underutilized by physicians. Underlying these facts is an intricate network of social, political, and cultural factors that have real consequences for dying patients and their families. In order to provide the highest quality EoL care, clinicians have to both recognize and reconcile the complex patient and physician factors influencing the dying experience. **Full text:** https://goo.gl/AJ6AUD

AMA

Roles of physicians in healthy dying

AMERICAN MEDICAL JOURNAL OF ETHICS, 2018;20(8):E675-792. What the roles of clinicians and patients should be in defining what constitutes a quality dying experience and good care of dying people has received less attention than issues like euthanasia and assisted death. Which parts of dying, if any, should be medicalized and why? What do patients and clinicians need to know about dying and why? This issue of the journal explores these and other questions. **Contents page:** https://goo.gl/KqoXfZ

Contents include:

Should physicians new to a case counsel patients and their families to change course at the end of life?

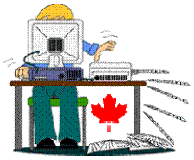
Four communication skills from psychiatry useful in palliative care (PC) and how to teach them

Which critical communication skills are essential for interdisciplinary end-of-life discussions?

AMA Code of Medical Ethics' opinions related to end-of-life care

For people dying to talk, it finally pays to listen with reimbursable advanced care planning

The role of hope, compassion, and uncertainty in physicians' reluctance to initiate PC



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

Home palliative service utilization and care trajectory among Ontario residents dying on chronic dialysis

CANADIAN JOURNAL OF KIDNEY HEALTH & DISEASE | Online – 24 July 2018 – The authors found that home palliative care (PC) services are infrequently used in this population and that, in most cases, used only within the last days of life. Their findings suggest that at present there is infrequent and late collaboration with home-based PC teams. They found, much like other studies, that palliative services were mostly used in end-of-life situations. Even when death is anticipated, patients most often do not appear to receive PC. In the authors' cohort, only 27% of patients who discontinued dialysis received home palliative services in the last year of life. In a recent survey of Ontario renal providers (nurses, physicians and social workers), the provincial mean score on a subscale measuring providers' propensity to engage community palliative services was only 2.5 out of 5.0,[1] suggesting room for improvement... **Full text:** https://goo.gl/tekuEf

1. Unpublished Ontario Renal Network data.

N.B. See 'The Ontario Renal Network Palliative Care Report: Recommendations towards an approach for chronic kidney disease.' (Undated) **Download/view at:** https://goo.gl/5cHahG

Noted in Media Watch 9 April 2018 (#558, p.9):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 April 2018 – **'Ten tips nephrologists wish the palliative care team knew about caring for patients with kidney disease.'** Many patients with chronic kidney disease (CKD) and end-stage renal disease have unmet palliative care (PC) needs. Physical and emotional symptoms are common. Written by nephrologists and PC clinicians, this article will help PC providers to have a richer understanding of kidney disease-related symptom burden, disease trajectory, prognosis, and barriers to hospice enrollment for patients with CKD and end-stage renal disease. **Abstract:** https://goo.gl/ZETT6G

N.B. Additional articles on palliative and end-of-life care for people living with chronic kidney disease noted in this issue of Media Watch.

Focus on the family: A case example of end-of-life care for an older LGBT veteran

CLINICAL GERONTOLOGIST | Online – 1 August 2018 – The Department of Veterans Affairs (VA) is likely the largest provider of health care for lesbian, gay, bisexual and transgender (LGBT) persons in U.S. However, histories of homophobia, stigma, discrimination, and past military policies have all had a lasting impact on the health of LGBT veterans. Effects can be seen across healthcare needs, disparities, access, and utilization for or by LGBT veterans. A case from a VA hospice unit is used to illustrate some challenges and opportunities when providing end-of-life (EoL) care for an older, lesbian veteran. This case highlights many of the unique needs and challenges that may arise in caring for LGBT veterans and their families at EoL. Abstract: https://goo.gl/8oK4Uz

N.B. Additional articles on end-of-life care for LGBT persons noted in the 25 June 2018 issue of Media Watch (#569, pp.13-14).

Palliative care: The need of the modern era

HONG KONG MEDICAL JOURNAL | Online – 30 July 2018 – Palliative care (PC) emerged a half century ago as an ethos based on compassion and care for patients and their families to relieve their suffering. It entails a paradigm shift from the biomedical model to the bio-psycho-spiritual model. Despite Hong Kong's relatively good local PC service coverage for patients who died of cancer and end-stage renal failure, service gaps for PC do exist among our ageing population with non-malignant life-limiting illnesses. The author strongly urge the Hong Kong Government to develop local PC policy in response to the World Health Assembly's resolution. Growing international and local evidence demonstrates the im-

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pacts of PC on patient outcomes, caregivers, and health care. Such outcomes can be service-based, disease-based, or symptom/suffering-based. The goal of PC is to relieve health-related suffering. Evidence-based management of pain, breathlessness, and psycho-spiritual suffering are discussed. Care in the end-of-life phase should be an integral part of PC, promoting patient choice, advance care planning, and good death. **Full text:** https://goo.gl/5rdr2c

> **N.B.** Additional articles on palliative and end-of-life care in Hong Kong noted in the 20 February 2017 issue of Media Watch (#500, p.13). The autonomous territory was ranked 22nd of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. [Noted in the 12 October 2015 issue of Media Watch (#431, p.6)] **Download/view at:** https://goo.gl/qeTWds

Variation in out-of-hospital death among palliative care inpatients across public hospitals in New South Wales, Australia

INTERNAL MEDICINE JOURNAL | Online – 24 July 2018 – Among 25,359 palliative care (PC) inpatients [i.e., patient population studied], 3,677 (14%) died out of hospital. The out-of-hospital death rate was lower for younger patients, males and those living in the most deprived areas; it was higher for cancer patients and those who received PC before their last admission. Hospital size, location and availability of hospice care unit were not a factor. Across hospitals, the median crude rate of out-of-hospital death was 14%... The majority of patients who received PC in hospital stayed in hospital until death. The variation in out-of-hospital death across hospitals was considerable and mostly remained unexplained. This variability warrants investigation into transition of PC between hospitals and communities to inform interventions. **Abstract:** https://goo.gl/5RFUpf

Increasing access to children's palliative care education through e-learning: A review of the ICPCN experience

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Online – 25 July 2018 – Education is integral to the development of children's palliative care (CPC) globally; thus, the International Children's Palliative Care Network (ICPCN) developed a training programme including face-to-face and e-learning programmes to increase access to CPC. A review of ICPCN's e-learning programmes was undertaken in April/May 2018. At the time of writing, there are seven courses available, with more scheduled to be released in the near future. All courses are available in English, with some available in other languages, including Mandarin, Czech and Dutch. Between May 2016 and April 2018, 1,501 individuals accessed the courses from 96 countries (39% nurses, 28% doctors). English was the prevalent language used (74%), followed by Spanish (8.5%). To date, over 3,106 participants have accessed the e-learning programme from 124 countries. An evaluation in 2015/2016 found that >80% of respondents said the courses were clear, understandable, rated them highly and found them useful. Some 75% of respondents reported improved knowledge, skills and change in attitude, while 61% reported a change in practice. The ICPCN e-learning platform is an innovative way of improving knowledge and understanding of CPC, thereby increasing the accessibility and availability of CPC. **Abstract (w. link to references):** https://goo.gl/Q52ppx

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 31 July 2018 – **'Research barriers in children and young people with life-limiting conditions: A survey.'** U.K. chief investigators (Cis) [i.e., study participants] cited limitations on funding, governance procedures including research and development, site-specific and research ethics committee approval processes, and clinician gatekeeping as challenges to research. CIs offered some solutions to overcome identified barriers such as working with children and young people and their families to ensure their needs are adequately considered in study design and communicated to ethics committees; and, designing studies with broad inclusion criteria and developing effective relationships with clinicians in order to overcome clinician gatekeeping. **Full text:** https://goo.gl/6uyJzC

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- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Inprint – Accessed 31 July 2018 – **'Place bonding in children's hospice care: A qualitative study.'** Limited knowledge exists of parents' perceptions and experiences of children's hospices and how these contribute to the varied access and uptake of services. A grounded theory of place bonding was developed which illustrates the cognitive journey taken by parents of children with life-limiting conditions considering/receiving hospice care for their child. Finding a place where they belonged and felt at "home" made the decision to accept help in caring for their child with a life-limiting condition more acceptable. The theory of place bonding offers children's hospices a new perspective from which to view how parents access, accept and build relationships at the hospice. **Abstract:** https://goo.gl/oYWrrr

- *PATIENT EXPERIENCE JOURNAL*, 2018;Issue 2:Article 5. **'Breaking bad news and the importance of compassionate palliative care of the infant.'** Bad news to parents regarding their infant is information that negatively impacts the parent's feelings and view of the present and/or future. The style of delivering bad news has a significant impact on the physician/parent relationship and the satisfaction of the family upon the healthcare team and palliative care (PC) system. In the case of an inevitable death of an infant, the implementation of PC follows the delivery of bad news. The strategy of PC and the philosophy of communication between the healthcare provider and family unit leave a lasting impression on the parents regarding the care of their infant. Clinicians should strive to educate themselves regarding the art of breaking bad news... **Full text**: https://goo.gl/Ye2bAc

  N.B. The focus of the current issue of *Patient Experience Journal* is the patient & family experience in children's hospitals and pediatric care. **Journal contents page:** https://goo.gl/eXUNvJ

The role of the healthcare chaplain: A literature review

JOURNAL OF HEALTH CARE CHAPLAINCY, 2018;24(3):87-106. Healthcare chaplains operate in many healthcare sites internationally and yet their contribution is not always clearly understood by medical and healthcare staff. This review aims to explore the chaplains' role in healthcare, with a view to informing best practice in future healthcare chaplaincy. Overall the extent of the provision and staffing of chaplaincy service internationally is unclear. From this review, several key spiritual and pastoral roles in healthcare emerge including a potential contribution to ethical decision making at the end of life. Healthcare chaplains are key personnel, already employed in many healthcare organizations, who are in a pivotal position to contribute to future developments of faith-based care, faith-sensitive pastoral, and spiritual care provision. They also have a new and evolving role in ethical support of patient, families and healthcare teams. **Abstract (w. link to references):** https://goo.gl/4DrKYF

Noted in Media Watch 2 April 2018 (#557, p.13):

- *JOURNAL OF RELIGION & HEALTH* | Online – 22 March 2018 – **'The role of healthcare chaplains in resuscitation: A rapid literature review.'** Chaplains role at the end of life (EoL), despite well described and supported, has received little empirical support. There is an emerging role for chaplains in healthcare ethics, supporting EoL decisions and supporting family witnessed resuscitation where relevant. Their role needs to be more clearly understood by medical staff, and chaplain's input into undergraduate medical education is vital. **Abstract (inc. list of references):** https://goo.gl/6mg2sc

N.B. Selected articles on the role of chaplains in the context of palliative and end-of-life care noted in the 29 May 2017 issue of Media Watch (pp.10-11). Selected articles on non-religious chaplains noted in the 23 July 2018 issue of the weekly report (#573, pp.4-5).

Palliative care education in U.S. adult neuro-oncology fellowship programs

JOURNAL OF NEURO-ONCOLOGY | Online – 2 August 2018 – Palliative care (PC) for patients with neuro-oncological diseases positively impacts morbidity and mortality. No studies have evaluated whether neuro-oncology fellows receive formal PC education during fellowship. Of 26 programs with fellows, 17 completed surveys (65% response rate) of which 3 (18%) offered no formal PC education. The methods most utilized were formal didactics (seminars/conferences) and self-directed reading materials. One-third of programs have developed their own teaching materials. Communication was the domain identified as

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Most important, the domain fellows were most well-trained in, and the domain programs directors (PDs) felt most comfortable providing for their own patients. Addressing spiritual distress and initiating life-prolonging therapies were the domains PDs identified as being least important, fellows were least well trained in, and PDs were least comfortable providing for their own patients. Most programs (83%) were satisfied with the PC education available at their program. Time for teaching and faculty availability were the most common barriers. **Abstract (inc. list of references):** https://goo.gl/crrxsT

Noted in Media Watch 18 December 2017 (#543, p.14):

- *CONTINUUM*, 2017;23(6):1709-1726. **'Palliative care, end-of-life care, and advance care planning in neuro-oncology.'** Management recommendations are made for neurologic symptoms in patients with advanced brain tumors... Special attention is given to how and when to involve subspecialty palliative care (PC) and hospice services to improve symptom management during active tumor treatment and in the end-of-life (EoL) phase of patients with brain tumors. Advance care planning and EoL goals should be addressed early in the disease trajectory; this article provides a road map for these discussions. **Abstract:** https://goo.gl/PTLtNG

N.B. Additional articles in palliative and end-of-life care in neuro-oncology noted in the 7 August 2017 issue of Media Watch (#524, p.13).

Complementary and alternative medicine in hospice and palliative care: A systematic review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online –1 August 2018 – When conventional therapies do not provide adequate symptom management or produce their own adverse effects, patients, families and caregivers may prefer complementary or alternative approaches in their care. Out of 4,682 studies, 17 were identified for further evaluation. Therapies included acupressure, acupuncture, aromatherapy massage, breathing, hypnotherapy, massage, meditation, music therapy, reflexology, and reiki. Many studies demonstrated a short-term benefit in symptom improvement from baseline with complementary and alternative medicines, although a significant benefit was not found between groups**. Abstract (w. link to references):** https://goo.gl/9tTspf

Early integrated palliative approach for idiopathic pulmonary fibrosis: A narrative study of bereaved caregivers' experiences

PALLIATIVE MEDICINE | Online – 30 July 2018 – Idiopathic pulmonary fibrosis has an uncertain and rapid trajectory after diagnosis. Palliative care is rarely utilized, although both patients and caregivers experience a distressingly high symptom burden. Most patients die in hospital. Five major themes were identified [in this Canadian study]: 1) Having a terminal disease; 2) Planning goals and wishes for care; 3) Living life and creating memories; 4) Feeling strain and responsibility; and, 5) Nearing the end. Caregivers [interviewed] had little understanding of prognosis prior to advance care planning (ACP) conversations at the clinic. ACP conversations enabled caregivers to know and support patients' goals and wishes. Caregivers described feeling informed, prepared, and supported when death was near. They expressed neither distress nor anxiety related to patients' symptoms or strain of relationships. Collaboration and close communication among caregivers, respirologists, and home care enabled effective symptom management and out of hospital deaths. Patients and caregivers had opportunities to enjoy events, create memories, determine preferences, and make plans. **Abstract:** https://goo.gl/BxM71s

Noted in Media Watch 23 October 2017 (#535, p.11):

- *THE LANCET: RESPIRATORY DISEASE* | Online – 12 October 2017 – **'Palliative care in interstitial lung disease: Living well.'** Progressive fibrotic interstitial lung diseases (ILDs) are characterised by major reductions in quality of life and survival, and have similarities to certain malignancies. However, palliative care (PC) expertise is conspicuously inaccessible to many patients with ILD. The incorrect perception that PC is synonymous with end-of-life care, with no role earlier in the course of ILD, has created a culture of neglect. **Full text:** https://goo.gl/yBaK5G

State of advance care planning research: A descriptive overview of systematic reviews

PALLIATIVE & SUPPORTIVE CARE | Online – 30 July 2018 – Eighty systematic reviews, covering 1,662 single articles, show that advance care planning (ACP) related research focuses on nine main topics: 1) ACP as part of end-of-life or palliative care interventions; 2) Care decision-making; 3) Communication strategies; 4) Factors influencing ACP implementation; 5) ACP for specific patient groups; 6) ACP effectiveness; 7) ACP experiences; 8) ACP cost; and, 9) ACP outcome measures. The majority of this research was published since 2014, its quality ranges from moderate to low, and reports on documentation, concordance, preferences, and resource utilization outcomes. Despite the surge of ACP research, there are major knowledge gaps about ACP initiation, timeliness, optimal content, and impact because of the low quality and fragmentation of the available evidence. Research has mostly focused on discrete aspects within ACP instead of using a holistic evaluative approach that takes into account its intricate working mechanisms, the effects of systems and contexts, and the impacts on multilevel stakeholders. **Abstract (inc. list of references):** https://goo.gl/RaB4FG

Communicating end-of-life care goals and decision-making among a multidisciplinary geriatric inpatient rehabilitation team: A qualitative descriptive study

PALLIATIVE MEDICINE | Online – 3 August 2018 – Recognising patient deterioration towards death is difficult, and not all clinicians are able or have the necessary clinical skills to do this. Nonetheless, patient deterioration, whatever the cause, is every clinician's responsibility to recognise and act upon. Key to facilitating a "good death" is comprehensive, clear and timely communication. This needs to take place with the multidisciplinary team, the patient and family. Communication of patient deterioration towards death among members of a multidisciplinary team underpins care-planning and a team approach to end-of-life care. In this regard, it is of utmost importance that educational opportunities be developed for clinicians to improve communication skills and learn about patient deterioration, the dying process and end-of-life care. **Full text:** https://goo.gl/JfLJye

Noted in Media Watch 2 July 2018 (#570, p.11):

- *PALLIATIVE MEDICINE* | Online – 29 June 2018 – '**Advance care planning: A systematic review about experiences of patients with a life-threatening or life-limiting illness.**' Of the 3,555 articles found, 20 were included in this review. The authors identified three themes in patients' experiences with advance care planning (ACP): 1) "Ambivalence" refers to patients simultaneously experiencing benefits from ACP as well as unpleasant feelings; 2) "Readiness" for is a necessary prerequisite for taking up its benefits, but can also be promoted by the process of ACP itself; and, "Openness" refers to patients' need to feel comfortable in being open about their preferences for future care towards relevant others. **Full text:** https://goo.gl/H5f4dk

Noted in Media Watch 1 January 2018 (#539, p.12):

- *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 completion. 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

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.

Quality of end-of-life care in patients with dementia compared to patients with cancer: A population-based register study

PLOS ONE | Online – 30 July 2018 – Globally, dementia is one of the leading causes of death. Given the growing elderly population in the world, the yearly number of deaths by dementia is expected to increase. Patients dying from dementia are reported to suffer from a burden of symptoms similar to that of patients with cancer, but receive less medication against symptoms, have a lower probability of palliative care (PC) planning and seldom have access to specialised PC. Studies investigating the quality of PC in dementia are scarce. The aim of this Swedish national study was to compare the quality of end-of-life care (EoLC) between patients with dementia and patients with cancer regardless of place of care. The findings indicate that patients dying from Alzheimer's disease and other types of dementia receive a poorer quality of EoLC concerning several important EoLC areas when compared to patients dying from cancer. Guidelines for EoLC in Sweden cannot explain or justify these differences. Further studies are needed to find possible ways to improve EoLC in the large and growing group of patients dying from dementia. **Full text:** https://goo.gl/3cdVRm

> **N.B.** Additional articles on palliative and end-of-life care for people living with Alzheimer's and other forms of dementia noted in the 9 July 2018 issue of Media Watch (#571, p.10).
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> Noted in Media Watch 8 July 2013 (#313, p.10):
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> - *PALLIATIVE MEDICINE* | Online – 4 July 2013 – **'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care.'** The authors provide the first definition of palliative care in dementia based on evidence and consensus, a framework to provide guidance for clinical practice, policy and research. A total of 64 (72%) experts from 23 countries evaluated a set of 11 domains and 57 recommendations **Full text:** https://goo.gl/1iY83K

Place of death in centenarians in Taiwan and the need for home hospice care

TAIPEI CITY MEDICAL JOURNAL | Online – Accessed 31 July 2018 – Taiwan represents one of the fastest aging countries in the world. Facing the end of life (EoL), the centenarians experience different causes of death as compared with younger elders. Usually, the centenarians' preference for place of death is outside the hospital in a homely environment. No study has ever considered the effects of hospice care on the place of death and cause of death among centenarians. Centenarians are more likely to die of pneumonia and frailty and less likely to die of cancers and cerebrovascular disease compared with younger elderly. The analysis of the 2002-2010 National Insurance Health Research Database indicated that 67-73% of the centenarians who passed away died at home while the number of centenarians who died in hospital continued to rise. Hospice home care for centenarians was inadequate compared with non-centenarians. To reduce the reliance on hospital care at the EoL, centenarians needs an enhancement of death literacy. General provision of advanced care planning and earlier intervention of home hospice care should be promoted... **Abstract:** https://goo.gl/8x62y6

> **N.B.** Chinese language article. Additional articles on palliative and end-of-life care in Taiwan noted in the 8 January 2018 issue of Media Watch (#545, p.13). Taiwan was ranked 6th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. [Noted in the 12 October 2015 issue of Media Watch (#431 (p.6)] **Download/view at:** https://goo.gl/qeTWds
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> Noted in Media Watch 28 May 2018 (#565, p.10):
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> - *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 22 May 2018 – **'Centenarians' end-of-life thoughts and plans: Is their social network on the same page?'** In nearly half of cases [studied], proxies misjudged whether the centenarian thought about end of life (EoL). Although only few centenarians perceived the EoL as threatening, and approximately one-quarter reported longing for death, proxies overestimated centenarians' reports on the former and underestimated the latter. **Abstracts:** https://goo.gl/Hqshg9

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Noted in Media Watch 6 February 2017 (#498, p.17):

- *ZEITSCHRIFT FÜR GERONTOLOGIE UND GERIATRIE* | Online – 31 January 2017 – '**Centenarians preparing for the end of life?**' The population of centenarians has grown in Germany, but has yet hardly been considered in research on dying and death. Due to their very old age centenarians are especially intensively confronted with the challenge of the end of life (EoL). The aim of this study was to analyze how centenarians handle the existential challenge of the EoL and which aspects are especially significant for them. **Abstract (inc. list of references):** https://goo.gl/tlsZYf

  N.B. German language article.

Noted in Media Watch 2 May 2016 (#460, p.6):

- *JOURNAL OF AGING & SOCIAL POLICY* | Online – 25 April 2016 – '**Meeting the needs of the growing very old population: Policy implications for a global challenge.**' The authors outline several approaches to develop evidence-based policies and programs tailored to the needs of very old adults and their families. They focus on three key topics essential to life care: importance of integrated care to meet the complex care needs of the very old; balance between formal and informal care; and, development of suitable places for living. **Abstract (w. link to references):** http://goo.gl/v2wBsi

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BIOLAW JOURNAL*, 2018;2:225-230. '**The struggle with death.**' The evaluation of the [Netherlands] Termination of Life on Request & Assisted Suicide Act makes it clear that no adequate solution may be offered to elderly people who are "through with life." If they suffer unbearably and lastingly, euthanasia or assisted suicide may be granted to them on the basis of a medical assessment, but it may be questioned whether these possibilities are sufficient. Perhaps even more pressing are the problems that are not limited to the elderly, where individuals who "suffer from life" are concerned. Their suffering cannot be gauged from a medical point of view, let alone be treated. The physician's role is limited in this respect, since the issues are largely of a non-medical nature and thus require another perspective than the decisive one. This brings with it that individuals have, on the basis of the present legislation, few to no options to have their suffering – and thereby their lives – terminated. By regulating assisted suicide it may become possible to find a solution for the dire cases whose suffering must at present last unabated. **Full text:** https://goo.gl/uDnt1i

- *HEALTH & QUALITY OF LIFE OUTCOMES* | Online – 31 July 2018 – '**Euthanasia, religiosity and the valuation of health states: Results from an Irish EQ5D5L valuation study and their implications for anchor values.**' Quality adjusted life years have become an integral part of resource allocation decisions in many healthcare systems. Despite this surprisingly little research effort has been devoted to analysing how beliefs and attitudes to hastening death influence preferences for health states anchored at "dead" and "perfect health." The authors examine how, inter alia, adherence to particular religious beliefs (religiosity) influences attitudes to euthanasia and how, inter alia, attitudes to euthanasia influences the willingness to assign worse than dead (WTD) values to health states using data collected as part of the Irish EQ5D5L valuation study. Religiosity was a significant determinant of attitudes to euthanasia and attitudes to euthanasia were a significant determinant of the likelihood of assigning WTD values. A significant negative correlation in errors between the two probit models was observed indicative of support for the hypothesis of endogeneity between attitudes to euthanasia and readiness to assign WTD values. **Full text:** https://goo.gl/BZ8Kyz

- *INTERCHANGE* | Online – 24 July 2018 – '**Medical assistance in dying: Implications for Canadian classrooms...**' The recent passing of legislation decriminalizing medically assisted suicide was a landmark in Canadian history. Since the law's passage, an average of four Canadians per day have chosen to die using medical assistance. With Canadians embracing this option of death, the authors argue that there will be moments in Canadian schools when this topic will be brought into the classrooms. They outline how children view death both emotionally and conceptually, as well as how teachers can discuss death in their classrooms. The purpose is to provide a brief explanation of the law, an expiation of how children view death, and a framework for how teachers may be prepared to broach the topic when raised in their classrooms. **Abstract (inc. list of references):** https://goo.gl/hJiygx

- *INTERNATIONAL JOURNAL OF COMPARATIVE SOCIOLOGY* | Online – 26 July 2018 – **'Public support for the right to euthanasia: Impact of traditional religiosity and autonomy values across 37 nations.'** This study attempts to answer the question of whether the mass support for the right to euthanasia is an expression of autonomy values rather than just a function of a low religiosity. Multi-level regressions demonstrate that both traditional religiosity and autonomy values have a high impact at the individual level, while at the country level only the effects of traditional religiosity are significant. Autonomy values have stronger association with attitudes to euthanasia in countries with higher levels of post-materialism. Multilevel path analysis demonstrates that the effect of religiosity is partially and weakly mediated by the values of autonomy at both levels. Although religiosity was found to have a much stronger impact, the independent effect of autonomy values suggests that mass support for the right to euthanasia is a value-driven preference for quality over quantity of life. The authors suggest that the fall in traditional religiosity might emphasize the role of values in moral attitudes regulation. **Abstract:** https://goo.gl/Qa9m8f

Journal Watch

European Journal of Palliative Care ceases publication

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (EAPC) | Online – Accessed 30 July 2018 – The Association has officially announced that Hayward Medical Communications, the publisher of the *European Journal of Palliative Care* (*EJPC*), is closing the journal after 24 years. Since the launch of the journal in 1994, the Association and the *EJPC* "forged a strong and mutually effective bond." Together, they provided members and readers with a wide range of papers, including several seminal EAPC White papers and the collected abstracts for many EAPC congresses. The collaboration also led to numerous posts on the journal's blog contributed by many of the *EJPC*'s authors providing additional background on their published articles; these can be downloaded/viewed at: https://goo.gl/zHBFPw

N.B. Address enquiries about editorial or subscription matters to the publisher at: https://goo.gl/WQSxHE

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Cont.

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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[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’]

Australia

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

[Scroll down to ‘International Websites’]

Canada

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

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

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

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

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

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

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

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

[Scroll down to ‘Palliative Care Network Community’]

Europe

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

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

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