

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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Quality of dying and death: Scroll down to [Specialist Publications](#) and 'Impact of high self-perceived burden to others with preferences for end-of-life care and its determinants for terminally ill cancer patients: A prospective cohort study' (p.14), in *Psycho-Oncology*.

Canada

End-of-life care in Manitoba

We must speak for those who can't

MANITOBA | *The Winnipeg Free Press* – 11 March 2016 – In Manitoba, even some of the best health facilities are simply not up to the job: Health Sciences Centre (HSC), for example, does many things well but delivering a “good” death is not its strong suit. HSC is an extraordinary facility. It is the largest health-care centre in the province, with nearly 8,000 staff and volunteers serving Manitoba, north-western Ontario and Nunavut. More people die at HSC than any other health-care facility in the province. Yet, HSC does not have a single, dedicated palliative care (PC) bed. There is no PC ward to offer the privacy and calm those dying patients and their families need and deserve. While a PC physician and nurse are on-site to give their advice upon request, there is no PC service working to address all forms of suffering – physical, psychological and existential – affecting patients and their families. <http://goo.gl/X9arqZ>

Numerous gaps in Ontario's system for palliative care, report finds

ONTARIO | *The Ottawa Citizen* – 11 March 2016 – The way Ontario's health system cares for the dying is full of holes that need patching, Ottawa South Member of the Provincial Parliament John Fraser says in an official report the provincial government is to use as a guide to those fixes.¹ The province is planning to spend \$25 million a year more on palliative care (PC), and Fraser is opening a “palliative care network.” He's an assistant to Health Minister Eric Hoskins, and was assigned the PC problem in 2014. He's been holding hearings and consultations across the province... “Despite the outstanding work being done by those in the PC sector, the simple fact is that not enough patients and families receive the PC, support and services they need as early as they need them, and in the most appropriate setting,” Fraser's report says. <http://goo.gl/GEFYP1>

1. 'Palliative & End-Of-Life Care Provincial Roundtable Report,' Ontario Minister of Health & Long-Term Care, March 2016. <http://goo.gl/eRyw8K>

N.B. See '2014 Report,' Office of the Auditor General of Ontario, December 2014, and extract on end-of-life care in the province (Chapter 3.08, pp.258-288). [Noted in Media Watch, 15 December 2014, #388 (p.2)] <http://goo.gl/swg8jz>

Doctors need to examine biases they may have against indigenous patients, report says

THE GLOBE & MAIL | Online – 6 March 2016 – Doctors need to examine any biases they may have against indigenous patients, says a new guidance document from the College of Family Physicians of Canada that addresses systemic racism in health care.¹ “It’s a silent topic, really,” said Darlene Kitty, one of the document’s authors. “People don’t like to see if there’s racism existing in the health-care system, but there definitely is.” It also says more education and training are key to addressing the issue. “It should start at the very beginning of medical school, or nursing school,” Dr. Kitty said. “Sometimes it boils down to lack of knowledge, lack of appreciation of the challenges that indigenous people face.” Dr. Kitty is the director of the Indigenous Program at the University of Ottawa, which teaches medical students about indigenous health and social issues to ensure they are applying cultural awareness and sensitivity to their work. Most medical schools have such components in their curriculums already, she said, although they are not mandatory. The Truth

& Reconciliation Commission has recommended that all levels of government augment “cultural competency training” in medical schools and the health system itself. <http://goo.gl/2lywTN>

Canada’s Most Vulnerable: Improving Health Care for First Nations, Métis and Inuit Seniors

HEALTH COUNCIL OF CANADA | Online – November 2013 – There is no funding for palliative/end-of-life care through the First Nations & Inuit Health Branch, and Health Canada’s First Nations and Inuit Home & Community Care program is unable to provide 24-hour support for palliative clients and their families due to limited staffing and funds. Research with seniors to define culturally appropriate end-of-life care yields a different perspective from the Western model. In some aboriginal cultures, death is part of life, and the care and comfort of heart and spirit take precedence over medical procedures and protocols. [Noted in *Media Watch*, 2 December 2013, #334 (pp.1-2)] <http://goo.gl/45MT6A>

1. ‘Health and Health Care Implications of Systemic Racism on Indigenous Peoples in Canada,’ College of Family Physicians of Canada, March 2016. <http://goo.gl/JRpDga>

Noted in *Media Watch*, 22 June 2015, #415 (p.14):

- **PALLIATIVE & SUPPORTIVE CARE** | Online – 15 June 2015 – ‘**Indigenous people’s experiences at the end of life.**’ The findings of this study provide a beginning to an understanding of the end-of-life experiences of indigenous peoples and a foundation for future research. More interpretive, qualitative research is critical if palliative care services, the healthcare system, and healthcare providers are to reduce barriers to “preparing the spirit” for the journey at the end of life. <http://goo.gl/Yk9GHN>

Governments should support caring for seniors in own homes – report

ONTARIO | *The Advertiser* (Grand Falls-Windsor) – 3 March 2016 – A recently released study by the Institute for Research on Public Policy suggests that, rather than increasing the number of residential care beds, governments should expand community-based care to help seniors remain in their homes.¹ Health & Community Services Minister Dr. John Haggie said the report ... aligns nicely with how he would like to see this province move forward in providing care to the elderly. The report draws on research from Ontario and abroad. The researchers feel

health care systems conceived decades ago are being challenged by the health and social care needs of an aging population with long-term disabilities. <http://goo.gl/gN8bj7>

Specialist Publications

‘**Dying with dignity: Bringing an essential service to Toronto’s homeless and vulnerably housed**’ (p.14), in *UBC Medical Journal*.

1. ‘Integrating Long-Term Care into a Community-Based Continuum: Shifting from “Beds” to “Places,”’ Institute for Research on Public Policy, February 2016. <http://goo.gl/GVH5ff>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | CTV News (Vancouver) – 10 March 2016 – ‘**Vancouver health authority changes assisted-dying guidelines for staff.**’ A major British Columbia health authority has updated its guidelines for medical staff on how to respond to requests for assisted death, allowing doctors and nurses to refer patients to a colleague. Vancouver Coastal Health first distributed a bulletin on 5 February that advised staff not to provide advice on assistance in dying, but to inform patients they may wish to speak with legal counsel as a court-ordered exemption may be granted. <http://goo.gl/H55B6o>
- PRINCE EDWARD ISLAND | CBC News (Charlottetown) – 8 March 2016 – ‘**Assisted dying guidelines issued by College of Physicians & Surgeons of Prince Edward Island.**’ “In the current absence of federal, provincial or territorial legislation related to physician assisted dying, it falls to the medical regulatory authorities in Canada to develop standards or guidance for physicians within their provinces or territories,” states the Policy on Physician-Assisted Dying. The document also states that when legislation is developed, it will supersede the document, and may lead to the document being revised. <http://goo.gl/GxjhHv>
- ONTARIO | *The Toronto Star* – 7 March 2016 – ‘**Names of doctors for 80-year-old Toronto man seeking assisted death cannot be published, judge rules.**’ A judge agreed ... to ban media from reporting the names of doctors for a Toronto man seeking assisted death, arguing that anonymity is needed to ensure health workers keep helping out in such cases. The ruling by Justice Thomas McEwen of the Ontario Superior Court also prohibits identifying the cancer patient and his family, citing the “intensely private and personal matter of his death.” <http://goo.gl/IPCfbX>
- *THE OTTAWA CITIZEN* | Online – 7 March 2016 – ‘**Editorial: Don’t forget palliative treatment.**’ An end to suffering and a dignified death: that’s what federal legislation on assisted dying is supposed to achieve. But the law now being crafted will fall short unless Parliament and the provinces act decisively on a key issue for which there is some agreement among political parties: strengthening palliative care. <http://goo.gl/JHkJE4>
- CBC NEWS | Online – 6 March 2016 – ‘**Deciding on assisted death in context of mental illness highly complex, experts say.**’ One of the most contentious issues sparked by Canada’s upcoming right-to-die legislation is whether people with mental illness should be eligible to seek a doctor’s help to end their lives, along with those suffering from a “grievous and irremediable” physical disease like terminal cancer. Last week, a parliamentary committee recommended that Canadians with psychiatric disorders that cause intolerable suffering should be included in any regulations governing physician-assisted death... “We know that society would not accept that people should be treated differently just because they have a different illness,” said Dr. Sonu Gaiind, president of the Canadian Psychiatric Association. “But the issue that we’re really concerned about ... is to make sure that there is full understanding of how in any assisted-dying framework, key processes that can be affected by mental illness are properly assessed,” he said, adding that it should be psychiatrists conducting the required evaluation. <http://goo.gl/XrsMAF>

Noted in Media Watch, 22 September 2015, #428 (p.3):

- SASKATCHEWAN | *The Star-Phoenix* (Saskatoon) – 14 September 2015 – ‘**Psychiatrists fear role as “suicide enablers.”**’ The Supreme Court of Canada ruling is creating deep discomfort in a field of medicine where “cures” are rare and where many worry there is every possibility severe depression and other mental illnesses could meet the test for assisted suicide as set out by the court. <http://goo.gl/qxUn9d>

Related

- *THE NATIONAL POST* | Online – 7 March 2016 – ‘**Physician-assisted dying debate highlights the need for better mental health services.**’ Physician-assisted dying is not a real “choice” for those with mental illness, if we don’t first offer them adequate care and support. And the unfortunate reality is that, in Canada, mental health is vastly under-served. <http://goo.gl/a4x4IU>

U.S.A.

When medicine and faith define death differently

THE ATLANTIC | Online – 10 March 2016 – Thirteen-year-old Ezadin Mahmoud was pronounced dead on 27 August 2014... His heart was beating and his breath was still warm, but his brain stem had been severed. He had been practicing backflips with his brothers when he landed on his head. If radioactive tracers were inserted in his veins, it would show his blood rerouting around the swollen brain stem, like water moving around a dead log. One might note how his pupils failed to respond to light. If removed from the ventilator, his breathing would slow to a halt. The doctors broke the news and wrote the death certificate, a tragic but closed case. However, Ezadin's father, Mahmoud Hassen, remained unconvinced of the doctors' verdict. In Somalia, where Ezadin's parents grew up, death was easier to define: No heartbeat. Breath that does not return. Skin that turns pale, then purple. Death was something you could see and feel. Like any parent, Mahmoud did not want to believe that his son was dead, but he also was not sure if taking his son off life support was in accordance with his faith. He was dead according to the doctors, but was he dead – had his soul (*nafs*) departed – according to Islamic law? <http://goo.gl/rjPB4j>

Noted in Media Watch 1 February 2016, #447 (p.13):

- *JOURNAL OF RELIGION & HEALTH* | Online – 22 January 2016 – ‘**Ethical dilemmas at the end of life: Islamic perspective.**’ Islamic law permits the withdrawal of futile treatment, including all kinds of life support, from terminally ill patients leaving death to take its natural course. However, such decision should only take place when the physicians are confident that death is inevitable. All interventions ensuring patient's comfort and dignity should be maintained. This topic is quite challenging for the health care providers of Muslim patients in the Western World. <http://goo.gl/9QCq9d>

N.B. Additional articles on Islam and end-of-life care are noted in this issue of Media Watch.

Report details senior health care that misses the mark

KAISER HEALTH NEWS | Online – 8 March 2016 – Quality over quantity. As people get older, their health care goals may shift away from living as long as possible to maintaining a good quality of life. In key areas, however, the medical treatment older people receive often doesn't reflect this change, according to a new study.¹ The wide-ranging report ... uses Medicare claims data to examine aging Americans' health care. Among other things, it identified five key areas where too many older people continue to receive treatments that don't meet established guidelines or, often, their own goals and preferences. Two of the five have to do with preventive care that may not benefit seniors: screening for breast and prostate cancer. The other three address care at the end of life: late referral to hospice care, time in the intensive care unit in the last six months of life and placing feeding tubes in patients with dementia. While the measures themselves are quite different, they each highlight the need for better communication and shared decision-making among patients, their families and their medical providers. “Where there are harms and benefits and people judge them differently, that's where the shared decision-making comes in,” said Dr. Julie Bynum, an associate professor at the Dartmouth Institute for Health Policy & Clinical Practice... <http://goo.gl/ujjJls>

1. ‘Our Parents, Ourselves: Health Care for an Aging Population,’ A Report of the Dartmouth Atlas Project, February 2016. [Noted in Media Watch, 22 February 2016, #450 (p.3)] <http://goo.gl/dcXa6C>

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 p.16.

In the last months or days, these treatments can make things worse

THE WASHINGTON POST | Online – 7 March 2016 – Medical advances bring the promise of extending life, but some of the treatments used in a person's last months, weeks or days – such as CPR for failing hearts, dialysis for failing kidneys and feeding tubes for those unable to nourish themselves – often do not provide more time and can worsen quality of life. Yet saying no to more treatment is tremendously hard to do, whether that decision is made by patients or by relatives for patients who are too infirm to express themselves. "People don't have a good way to think about end of life," said Leslie Blackhall, associate professor of internal medicine at the University of Virginia Health System... "If we tell people, 'Chemo isn't going to help you,' they

still want it. We [all] want a peaceful, comfortable, dignified death . . . but not yet," she said. So what has research found about commonly used end-of-life interventions? Which ones can be useful and which are not, and when should they be administered? <https://goo.gl/IJNPya>

[Specialist Publications](#)

'Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review' (p.14), in *Palliative Medicine*.

Hospice fraud becoming a costly problem for Medicare

PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 6 March 2016 – No one knows how big the problem of hospice fraud is – all types of improper Medicare payments are estimated at \$65 billion for 2010 – but federal investigators prosecuted more than 60 cases in the last year alone, involving hundred of millions of dollars nationwide. The system that was built to help dying patients live out their remaining days with dignity and comfort has few quality metrics to meet, no minimum requirements for how often care is provided, and low barriers to getting into the business. Critics say that can make end-of-life care seem ripe for abuse. Hospice became a Medicare benefit in 1983 for people with terminal conditions who had less than six months to live. Some of the biggest health care expenses occur at the end of life, so the thinking was the program would also wind up saving the government money as people turned away from costly end-of-life care that often had little benefit. Instead, hospice spending has ballooned – more than quadrupling to \$15.1 billion in 2012 from \$2.9 billion in 2000 without denting overall Medicare spending, according to the Medicare Payment Advisory Commission, an independent agency that advises Congress on matters involving the federal health care program. The ground rules offer clues about how such a noble idea could go so wrong. <http://goo.gl/qKILre>

Noted in Media Watch, 25 January 2016, #446 (p.15):

- *AMERICAN CRIMINAL LAW REVIEW* | Online – Accessed 19 January 2016 – '**Life, death and Medicare fraud: The corruption of hospice and what the private public partnership under the Federal False Claims Act is doing about it.**' On 17 October 2013 a federal jury in the U.S. District Court for the Eastern District of Pennsylvania returned a guilty verdict on all thirty five counts against Matthew Kolodesh for various forms of healthcare fraud, mail fraud, money laundering, aiding and abetting, and conspiracy, related to his ownership and operation of Home Care Hospice of Philadelphia, Pennsylvania. The indictment alleged that Kolodesh and his co-conspirators fraudulently billed Medicare to the tune of an estimated \$12.8 million for end-of-life care for patients who were not at the end of their lives. <https://goo.gl/K5b9Bi>

[Media Watch: Palliative Care Network-e Website](#)

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <http://goo.gl/8JyLmE>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *Law Street* – 11 March 2016 – ‘California becomes fifth state to pass right to die legislation.’ California joins Vermont, Oregon, Washington, and Montana to become the fifth state to pass this type of legislation. The End of Life Option Act will go into effect on 9 June... The law requires those seeking end of life treatment to be cleared by two physicians who agree that the patient has six months or less to live. It also requires patients to be able to swallow the medication themselves and affirm in writing that they will do so 48 hours prior to taking the medication. This ensures that the individual is aware of the decision that they are making. <http://goo.gl/YBnzys>

Extract from *Law Street* article

It is legal in every U.S. state for an individual to create an advance directive that requires the withdrawal of treatment under any conditions the person wishes and for a patient to refuse any treatment or to require any treatment to be withdrawn... And perhaps least understood, for anyone who is dying in discomfort, it is currently legal in any U.S. state to receive palliative sedation, wherein the dying person is sedated so discomfort is relieved during the dying process.

International

End-of-life care in England

Hospice Haven House reaches out to Redbridge’s Sikh community

U.K. (England) | *The Ilford Record* – 10 March 2016 – Haven House chief executive Mike Palfreman said: “For parents looking after a seriously ill child, the support provided by a hospice can make an immeasurable difference. Many of our children and families live in the London Borough of Redbridge, which is also home to one of the largest Sikh populations in the capital. The size of this population is not reflected in the number of Sikh families who use Haven House.” <http://goo.gl/3xGnTx>

Noted in Media Watch, 3 June 2013, #305 (p.10):

- *HEALTH CARE ANALYSIS* | Online – 30 May 2013 – ‘Understanding and coping with diversity in healthcare.’ This paper describes the Sikh community and the provision of palliative care in hospitals and hospices. Although, the majority of patients classifying themselves as Sikhs have a shared language and history, they can also be divided on a number of lines such as caste affiliation, degree of assimilation in the west, educational level and whether baptized or not, all of which influence their beliefs and practices and hence impact on their needs from a health provider. <http://goo.gl/9J5zYQ>



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>

End-of-life care in Scotland

U-turn as Hospice At Home service is spared the axe in Fife

U.K. (Scotland) | *The Courier* (Dundee) – 10 March 2016 – National Health Service Fife has announced the project to fast-track terminally ill patients out of hospital to allow them to die with dignity at home will continue for another year. The move comes just days after the board said it would not stump up the £300,000 needed to extend the successful two-year pilot it ran jointly with Marie Curie Cancer Care. Health bosses had been under intense pressure to continue the arrangement, which doubled the number of dying Fifers able to leave hospital, and had been in talks with Marie Curie about the possibility of starting a new initiative. <http://goo.gl/dVChhH>

[Specialist Publications](#)

'Community nursing quality indicators for end-of-life care in England: Identification, preparation, and coordination' (p.9), in *British Journal of Community Nursing*

'What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the U.K.? Health care professional perspective' (p.9), in *Dementia*.

Noted in Media Watch, 7 March 2016, #452 (p.6):

- U.K. (Scotland) | *The Courier* (Dundee) – Online – 3 March 2016 – '**Hospice At Home service for terminally ill patients to be axed in Fife.**' A £1 million pilot project that gives people with terminal illnesses the chance to die at home is to be axed at the end of the month. <http://goo.gl/wLpbtu>

Hospital deaths in England

All hospital deaths to be examined by second doctor

U.K. (England) | *The Guardian* – 9 March 2016 – All deaths in hospital will be examined by a second doctor unconnected to the patient's treatment, in a move intended to improve care and help bereaved relatives understand why their loved one died. Jeremy Hunt, the health secretary ... will announce the change ... to take effect in England in 2018... From 2018 doctors acting as expert medical examiners will review and confirm the cause of all the 250,000 deaths a year that occur in hospital. They will be medics who already work at the National Health Service trust but in another department to the one in which the patient died ... they will provide "a second look" at events preceding the death, although doctors involved in looking after the patient who has died will continue to be the ones who certify the death and list the cause or causes of death on the death certificate. <http://goo.gl/JDj1eK>

End-of-life care in England

Dying well depends on where you live

U.K. (England) | London Assembly Health Committee – 8 March 2016 – Does good end of life care (EOLC), depend on your age, whether you live alone, your diagnosis or economic status? Does it depend on which London borough you live in? The London Assembly Health Committee has investigated the important issue of EOLC and it has found: only 8 out of 33 London Clinical Commissioning Groups (CCGs) scored above the national average for EOLC quality indicators and fewer than half of local authorities include EOLC within their Health & Wellbeing Strategies. CCGs spend a wide range of money on each death, the least spent £540 per death and the most spent £3,740 per death; 70% of hospitals in London cannot provide specialist palliative care (PC) services seven days a week and only 24% of London patients accessing PC have a non-cancer diagnosis. <https://goo.gl/2HIQzo>

N.B. Scroll down to 'Related Documents' to download 'End-of-Life Care in London,' London Assembly Health Committee, March 2016.

Cont.

Noted in Media Watch, 26 October 2015, #433 (p.6):

- U.K. (England) | Pan-London End of Life Alliance – 19 October 2015 – **‘Is London the worst place to die?’** A report by the Economist Intelligence Unit ranked the U.K. as the best country in the world for end-of-life care (EOLC) services.¹ However, the quality of EOLC received in London currently underperforms against national averages.² The London Assembly Health Committee will examine EOLC in the capital and the barriers certain groups face. <http://goo.gl/rMvweZ>
 1. ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/wcwa0l>
 2. ‘A review of specialist palliative care provision and access across London,’ London Cancer Alliance, PallE8 & Marie Curie, 18 September 2015. [Noted in Media Watch, 21 September 2015, #428 (p.5)] <https://goo.gl/Gacy6g>

Related

- U.K. (England) | *The Guardian* – 6 March 2016 – **‘Hospice UK attacks plan to extend National Health Service charges for non-European Union patients.’** The hospice movement has condemned moves by the Department of Health ... to include end-of-life care in its plans to widen charges for treating overseas visitors and migrants using the National Health Service (NHS). Hospices, for which NHS funding amounts only a third of adult care and 17% for children’s, are furious. <http://goo.gl/dBqPI4>

[Specialist Publications \(e.g., in-print and online journal articles, reports, etc.\)](#)

A 40-year history of end-of-life offerings in U.S. medical schools: 1975-2015

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 10 March 2016 – At 5-year intervals, beginning in 1975, U.S. medical schools were surveyed ... to determine their end-of-life (EOL) offerings. The inclusion of EOL topics has definitely expanded over the 40-year period as findings reveal that U.S. undergraduate medical students are currently exposed in over 90% of programs to death and dying, PC, and geriatric medicine, with the emphasis on these topics varying with the medical programs. <http://goo.gl/pa3cCV>

The size of the population potentially in need of palliative care in Germany An estimation based on death registration data

BMC PALLIATIVE CARE | Online – 8 March 2016 – Based on existing population-based methods ... German death registration data were analyzed and contrasted with international results. The data include all death cases in 2013 in Germany. Between 40.7 % (minimal estimate) and 96.1 % (maximal estimate) of death cases could benefit from palliative care (PC). The estimation ... results in 78.0 % of death cases potentially being eligible for PC. The percentage of potential PC candidates is conditioned by age. In the age category between 30 and 39 years, a potential demand for PC can be found for 40.4% percent of all deaths occurring in this age category, with this number increasing to 80.3 % in the age bracket of 80 years and over. <http://goo.gl/cP6BIU>

The use of reflective diaries in end of life training programmes: A study exploring the impact of self-reflection on the participants in a volunteer training programme

BMC PALLIATIVE CARE | Online – 5 March 2016 – The diaries facilitated an open dialogue between the volunteers, training leads and the researcher, and offered the opportunity to explore the volunteers’ understanding of the course content together with an account of their learning processes on a sessional basis. The volunteers’ reflections have been a driving influence in the revision and development of the education and training programme, which will now be used to train a further cohort of participants. For example, whilst the pilot reinforced the value of reflection, it also highlighted that the skill of reflection is not a given. <http://goo.gl/aiBEnA>

Community nursing quality indicators for end-of-life care in England: Identification, preparation, and coordination

BRITISH JOURNAL OF COMMUNITY NURSING | Online – 4 March 2016 – This article examines the quality priorities commissioners sought to incentivise in end-of-life care (EOLC), by reviewing a survey of Commissioning for Quality & Innovation (CQUIN) indicators for community nursing conducted in England in 2014-2015. Findings suggest EOLC was not given a high priority with the CQUIN indicators for community nursing. Vigorous quality standards, including training and development, need to be in place to make sure that the potential of community nursing is being used to sensitively engage with people nearing the end of their lives and support them to plan their future care, if they so wish. <http://goo.gl/is9aNv>

What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the U.K.? Health care professional perspective

DEMENTIA | Online – 1 March 2016 – People with advanced dementia are frequently bed-bound, doubly incontinent, and able to speak only a few words. Many reside in care homes and may often have complex needs requiring efficient and timely response by knowledgeable and compassionate staff. The aim of this study is to improve understanding of health care professionals' attitudes and knowledge of the barriers to integrated care for people with advanced dementia. Barriers ... are influenced by governmental and societal factors which contribute to challenging environments in care homes, poor morale amongst care staff, and a fragmentation of health and social care at the end of life. Quality of care for people with dementia as they approach death may be improved by developing collaborative networks to foster improved relationships between health and social care services. <http://goo.gl/ZW4FG1>

Challenging aspects of bereavement and grief in older adults with dementia: A case series and clinical consideration

JOURNAL OF GERONTOLOGY & GERIATRIC RESEARCH | Online – Accessed 8 March 2016 – Normal grief reactions of denial, anger, bargaining, depression and acceptance can be experienced in early dementia. As the disease progresses, persons with dementia (PWD) may be too cognitively impaired to experience and express their grief. A vague sense that something is wrong with inner distress may manifest as behavioural disturbances, for although cognition declines, feelings and states of emotional pain remain. PWD may not be aware of the loss or may confuse the present loss with earlier losses. Seemingly non-reactions of mourning were noted to be much more common than those found among persons with normal intellectual ability. <http://goo.gl/N98TAV>

Related

- *END OF LIFE JOURNAL* | Online – 4 March 2016 – ‘**Care home or home care? Difficult decisions for people with dementia and their carers.**’ This article will discuss reasons why family/friends of people with dementia want to care for their loved one at home, their perceptions of care homes, the need to open up discussions about place of care early in the disease trajectory and some of the advantages of care homes. In so doing, it will draw on issues raised by carers who participated in Alzheimer's Society's Carer Information & Support Programme. <http://goo.gl/Y1xcoH>

Noted in Media Watch, 9 November 2015, #435 (p.10):

- *BMC PALLIATIVE CARE* | Online – 4 November 2015 – ‘**Identification of the palliative phase in people with dementia: A variety of opinions between healthcare professionals.**’ Eighty-four health professionals working in 13 long-term care settings from six countries were asked to discuss when they considered people with dementia eligible for palliative care (PC). Three different time points in the disease trajectory were considered to be eligible for PC: 1) Early; 2) When signs and symptoms of advanced dementia are present; and, 3) From the time point that curative treatment of co-morbidities is futile. Yet, none of these time points was uniformly considered by the professional teams across Europe. In some cases, professionals working in the same nursing home didn't even reach consensus when considering persons with dementia eligible for PC. <http://goo.gl/MQ0nPu>

Cont.

Noted in Media Watch, 27 July 2015, #420 (p.12):

- *BMC PALLIATIVE CARE* | Online – 25 July 2015 – ‘**Expert views on the factors enabling good end-of-life care for people with dementia: A qualitative study.**’ Four key factors were identified from the expert interviews: 1) Leadership and management of care; 2) Integrating clinical expertise; 3) Continuity of care: and, 4) Use of guidelines. Leadership and management of care have implications for the successful implementation of guidelines, while the appropriate and timely use of clinical expertise could prevent hospitalisation and ensure continuity of care. A lack of integration across health and social care can undermine continuity of care. <http://goo.gl/dyvnB2>

N.B. See the issue of Media Watch 15 June 2015, #414 (pp.13-14), for selected articles on end-of-life care for people living with dementia.

End-of-life care decisions for haemodialysis patients – “We only tend to have that discussion with them when they start deteriorating”

HEALTH EXPECTATIONS | Online – 10 March 2016 – Prognosis is not routinely discussed with patients, in part due to a difficulty in estimation and the belief that patients do not want or need this information. Advance care planning is rarely carried out, and end-of-life care (EOLC) discussions are seldom initiated prior to patient deterioration. There is variability in end-of-life practices amongst nephrologists; some patients are felt to be withdrawn from dialysis too late. Furthermore, the possibility and implications of withdrawal are not commonly discussed with well patients. Critical barriers hindering better EOLC involvement for these patients are outlined. The study provides insights into the complexity of end-of-life conversations and the barriers to achieving better end-of-life communication practices. The results identify opportunities for improving the lives and deaths of haemodialysis patients. <http://goo.gl/3QY4iP>

Selected articles on end-of-life care for people living with chronic kidney disease

- *CLINICAL JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY* | Online – 12 August 2014 – ‘**A palliative approach to dialysis care: A patient-centered transition to the end of life.**’ This commentary elucidates what comprises a palliative approach to dialysis care and describes its potential and appropriate use. [Noted in Media Watch, 18 August 2014, #371 (p.8)] <http://goo.gl/6zVbGS>
- *AMERICAN JOURNAL OF KIDNEY DISEASES*, 2014;63(6):913-927. ‘**Thematic synthesis of qualitative studies on patient and caregiver perspectives on end-of-life care in chronic kidney disease.**’ The authors suggest that chronic kidney disease management should encompass palliative care strategies that promote emotional resilience, sense of well-being, and self-value. Also, respectful and attentive communication may empower patients to convey their values and preferences about their own care. [Noted in Media Watch, 9 June 2014, #361 (p.12)] <http://goo.gl/DRg0GG>
- *JOURNAL OF RENAL CARE* | Online – 18 January 2014 – ‘**Pathways to palliative care for patients with chronic kidney disease.**’ Whilst renal healthcare professionals support early discussion of end-of-life care at pre-dialysis education, congruity with the patient and family when making the final decision is of great importance. [Noted in Media Watch, 27 January 2014, #342 (p.9)] <http://goo.gl/7nwH3y>

Short break and emergency respite care: What options for young people with life-limiting conditions?

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2016;22(2):57-65. Access to appropriate short break and emergency respite care is required to prevent lifelong negative consequences for young people with life-limiting conditions, their family and society. In this study, there were few, or no, appropriate short break and emergency respite care alternatives when children’s hospice care was not available that can meet the need of young people with life-limiting conditions, creating anxiety for children’s hospice users and those leaving the service as a result of reaching transition age or through no longer meeting the children’s hospice eligibility criteria. <http://goo.gl/oatnbx>

Cont.

Noted in Media Watch, 7 December 2015, #439 (p.8):

- **CHILD: CARE, HEALTH & DEVELOPMENT** | Online – 7 November 2015 – ‘**Parental decision-making on utilisation of out-of-home respite in children’s palliative care: Findings of qualitative case study research – a proposed new model.**’ The proposed model offers an opportunity to identify how these decisions are made and may ultimately assist in identifying the elements of responsive and family-focused respite that are important to families of children with life-limiting conditions. Each family [i.e., study participant] reported vastly different needs and experiences of respite from their own unique perspective <http://goo.gl/u2PoA1>

Related

- **BMC PALLIATIVE CARE** | Online – 9 March 2016 – ‘**When parents face the death of their child: A nationwide cross-sectional survey of parental perspectives on their child’s end-of life care.**’ This is one of the few studies that quantitatively described and explored parental experiences related to their child’s end-of-life care (EOLC) in a [Swiss] population-based sample of bereaved mothers and fathers of children from the major diagnostic groups in which childhood deaths occur. Overall, parental scores on their experiences and perceived satisfaction with their child’s end of life care were high... Parents of a child with cancer rated their experiences highest ... and reported the highest satisfaction with care. The lowest scores were mainly reported by parents from the neurology group, with the exception of the domain *shared decision making*, where parents of neonates reported significantly less positive experiences. <http://goo.gl/0DXSZI>
- **PALLIATIVE MEDICINE** | Online – 7 March 2016 – ‘**Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study.**’ Four themes represented the prevalent experiences of parents: 1) Trapped inside the house; 2) The protector; 3) Living with the shadow; and, 4) Travelling a different pathway. They describe parents’ physical and social isolation, exclusion from the workforce, pervasive grief and associated impacts to their health and well-being. Limited professional and diminished social supports resulted in full ownership of care responsibility. Yet, parents embraced their role as “protector,” reporting acquired meaning and purpose. <http://goo.gl/We37gb>

[Media Watch: Editorial Practice](#)

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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.

Preventability and causes of readmissions in a national cohort of general medicine patients

JAMA INTERNAL MEDICINE | Online – 7 March 2016 – Approximately one-quarter of readmissions are potentially preventable when assessed using multiple perspectives. High-priority areas for improvement efforts include improved communication among health care teams and between health care professionals and patients, greater attention to patients' readiness for discharge, enhanced disease monitoring, and better support for patient self-management. The authors estimates of readmission preventability are within the ranges suggested by other researchers, but extend previous work in important ways. Their review process linked a comprehensive picture of clinical care, one that included viewpoints of patients, to a rigorous case review process that sought to identify not only readmission preventability but also opportunities for improvement. The process whereby the authors identified potential improvement targets also represents an important feature of their work. That is, their focus on an ideal health system lens for determining preventability provides a safeguard against fatalistic interpretations of readmissions as "non-preventable" or solely owing to advancing illnesses, while also allowing us to identify factors that should be addressed so that improvement leads toward an "ideal." <http://goo.gl/R1GWSj>

Commentary

- *JAMA INTERNAL MEDICINE* | Online – 7 March 2016 – The HomeRuN study also identified three factors that contributed to a substantial proportion of potentially preventable readmissions but that have not received as much attention. First, we need to test how to improve advanced care planning around the time of care transition, given the burden of hospitalizations toward the end of life. There are many opportunities to test innovative approaches that would facilitate cross-site palliative care consultation, greater input of a patient's outpatient health care provider during hospitalization, and better communication of advanced care plans to the in-patient team. <http://goo.gl/mPhBSy>

Integrated onco-palliative care associated with prolonged survival compared to standard care for patients with advanced lung cancer: A retrospective review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 3 March 2016 – The authors performed retrospective analysis of their partially integrated onco-palliative care lung cancer clinic to evaluate overall survival and resource utilization. Early palliative care (EPC) in advanced lung cancer was associated with a nearly two-month survival advantage compared to standard oncologic care. This finding provides supportive evidence to previously published reports of survival benefit with EPC intervention. Clinical trial participation rates in advanced lung cancer are lacking and the authors found more frequent clinical trial participation in the early PC group. No differences were seen in chemotherapy utilization or hospice enrollment. EPC patients' longer hospice length of stay did not compromise survival. <http://goo.gl/dxHhuD>

Avoidable for whom? Hospital use at the end of life

PALLIATIVE MEDICINE, 2014;28(7):917-918. A policy concern in many countries is reducing the number, and length, of acute hospital admissions among people who are at the end of life. This is typically presented as a "win-win" situation as a "good death" is viewed as hard to achieve in a hospital setting. Papers in this edition of *Palliative Medicine* add to a growing body of evidence which indicates, while this argument may appear both appealing and straightforward on paper, the realities of dying are more complex and unpredictable.^{1,2} [Noted in Media Watch, 9 June 2014, #361 (p.11)] <http://goo.gl/dcAGIO>

1. 'What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses,' *Palliative Medicine*, 2014;28(7):941-948. [Noted in Media Watch, 24 February 2014, #346 (p.13)] <http://goo.gl/XaTySH>
2. 'General practitioners' perspectives on the avoidability of hospitalizations at the end of life: A mixed method study,' *Palliative Medicine*, 2014;28(7):949-958. [Noted in Media Watch, 7 April 2014, #352 (p.13)] <http://goo.gl/hviNaj>

Cont.

Noted in Media Watch, 7 September 2015, #426 (p.15):

- *LUNG CANCER* | Online – 28 August 2015 – ‘**Integrating early palliative care in the management of lung cancer: The role of the thoracic oncologist.**’ Early introduction of palliative care in the management of patients with metastatic lung cancer is recommended since it improves quality of life and improves survival rates. How is early palliative care (EPC) in this setting implemented in daily oncologic care? In this review the authors want to determine the assignments for the thoracic oncologist in EPC and to give some practical tools how they started EPC in collaboration with the palliative team. <http://goo.gl/FH0XTX>

Noted in Media Watch, 4 February 2013, #291 (p.8):

- *JAMA INTERNAL MEDICINE* | Online – 28 January 2013 – ‘**Early palliative care in advanced lung cancer: A qualitative study.**’ The authors conducted a qualitative analysis of data from a randomized controlled trial that demonstrated improved quality of life, mood, and survival in patients with newly diagnosed metastatic non-small cell lung cancer who received early PC integrated with standard oncologic care versus standard oncologic care alone. <http://goo.gl/n36Z7t>

End-of-life care in France

The “palliative approach”: 10 years on

MÉDECINE PALLIATIVE | Online – 12 March 2016 – The “palliative approach” is a concept developed in France in 2002. It has been practiced in hospitals since 2004, with the goal of giving palliative care (PC) to the maximum number of persons at the end of life who are hospitalized in acute care services. The objective of this article, based on a literature review, is to report on progress over 10 years (2005–2015) in the dissemination of this initiative and to highlight both successful experiences as well as hindering factors, in order to make a number of recommendations and identify future lines of investigation. In particular, mechanisms should be set up for evaluating the quality of care and thus the efficient use of resources allocated to facilities willing to follow this course. Parallel to the current dynamics, we need to reinforce PC services in facilities caring for the dependent elderly where needs, already high, will necessarily increase with the aging of the population. <http://goo.gl/GKRmxG>

Noted in Media Watch, 5 October 2015, #430 (p.12):

- *MÉDECINE PALLIATIVE* | Online – 1 October 2015 – ‘**Pediatric palliative care in France: From yesterday to tomorrow.**’ Based on their personal experiences in intensive care and neurology ... the authors sought to retrace the evolution of the pediatric palliative approach from its origins to the present day. This is done through the lens of both the carers and the parents. Through this unique perspective, they describe the changes they have seen and present the challenges pediatric palliative care will face in the future. <http://goo.gl/mhmtU3>

N.B. French language articles. France was ranked 10th of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/sNQmn3>

The new forms of mourning: Loss and exhibition of the death on the Internet

OMEGA: JOURNAL OF DEATH & DYING | Online – 10 March 2016 – According to some specialists, ceremonial funeral practices are inclined to disappear, particularly as death is an object of repression in contemporary society. However, it seems that new forms of rituals are developing through modern technologies. Virtual tombs, memorial web pages, and the celebration of death anniversaries are now common currency on the Internet. Nonetheless, the overexposure favored by the Web seems to question traditional ways of “living out” one’s grief, subjecting the living and the dead to a redefinition of concepts of time and space, and entailing new forms of interaction. <http://goo.gl/pSH3Mt>

Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review

PALLIATIVE MEDICINE | Online – 7 March 2016 – Administration of non-beneficial life-sustaining treatments in terminal elderly patients still occurs due to lack of knowledge of patient's wishes or delayed physician-family communications on preference. Twenty-four articles from 10 countries, including 23,914 subjects, met the inclusion criteria... Perceived effectiveness of advance care documentation (ACD) in encouraging EOL discussions appears to be high, but is mostly derived from low-level evidence studies. This may indicate a willingness and openness of patients, surrogates and staff to perceive advance directives as an instrument to improve communication, rather than actual evidence of timeliness or effectiveness from suitably designed studies. The assumption that ACDs will lead to higher physicians' confidence or engagement in communicating with patients/families could not be objectively demonstrated in this review. <http://goo.gl/1JDdAH>

Related

- *ANNALS OF FAMILY MEDICINE*, 2016;14(2):125-132. '**Advance care planning meets group medical visits: The feasibility of promoting conversations.**' This study describes a pilot demonstration of a group visit for advance care planning (ACP) that engages patients in detailed conversations by providing a safe and supportive environment. Most participants evaluated the group visit as better than usual clinic visits for discussing ACP. Participants were willing to share personal values and challenges related to ACP and initiated discussions about a broad range of related topics. <http://goo.gl/h070oi>

Impact of high self-perceived burden to others with preferences for end-of-life care and its determinants for terminally ill cancer patients: A prospective cohort study

PSYCHO-ONCOLOGY | Online – 7 March 2016 – Self-perceived burden to others (SPB) is a major concern of terminally ill cancer patients and is frequently factored into end-of-life care (EOLC) decision-making. However, changes in and determinants of SPB and its longitudinal impact on preferences for EOLC over the dying process have not been investigated. Prevalence of high SPB [among study participants] increased as death approached... High SPB was precipitated by women, younger age, having inadequate financial resources, without religious affiliation, and suffering from severe symptom distress and heavy functional dependence, but was independent of time proximity to patient death, disease characteristics, and social support. Furthermore, high SPB was not associated with EOLC preferences, whether aggressive life-sustaining treatments or hospice care. High SPB was prevalent among terminally ill cancer patients but independent of preferences for EOLC. Cancer patients' SPB may be lessened by adequate symptom relief to facilitate functional independence. <http://goo.gl/kZxLNM>

Noted in Media Watch, 15 August 2011, #214 (p.7, under 'Worth Repeating'):

- *PALLIATIVE MEDICINE*, 2007;21(2):115-128. '**Feeling like a burden to others: A systematic review focusing on the end of life.**' There is a small but growing body of evidence to suggest that worry about creating burden to others is a common and troubling concern for people who are nearing the end of their lives. This review revealed that self-perceived burden is reported as a significant problem by 19-65% of terminally ill patients. It is correlated with loss of dignity, suffering, and a "bad death." <http://goo.gl/ZNAV9t>

Dying with dignity: Bringing an essential service to Toronto's marginalized homeless and vulnerably housed

UBC MEDICAL JOURNAL (University of British Columbia), 2016;7(2). Homeless persons and the vulnerably housed live significantly shorter lives and experience higher rates of chronic disease, mental illness and polysubstance abuse. Despite the high mortality and morbidity, this vulnerable and marginalized population continues to have difficulty accessing essential services such as palliation and end-of-life care. <http://goo.gl/DaRJDz>

Cont.

Noted in Media Watch, 23 November 2015, #437 (p.9):

- **BMC PALLIATIVE CARE** | Online – 18 November 2015 – ‘**Minding the gap: Access to palliative care and the homeless.**’ Our current palliative care (PC) delivery system requires a degree of monetary, in-person, and infrastructure support that often creates barriers for the homeless population; barriers they simply cannot overcome. McNeil *et al* have called for the creation of initiatives that cater to the needs of the poor by adopting flexible, low-threshold strategies, partnering with local community agencies, and by strengthening the training on end-of-life care issues amongst those who care for the homeless population.¹ <http://goo.gl/nBFksK>
 1. ‘Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals,’ *BMC Palliative Care*, 15 September 2012. [Noted in Media Watch, 17 September 2012, #271 (p.7)] <http://goo.gl/EC53H9>

Noted in Media Watch, 16 February 2015, #397 (p.10):

- **DEATH STUDIES** | Online – 12 February 2015 – ‘**What constitutes a good and bad death? Perspectives of homeless older adults.**’ In this study the themes identified for a good death were: 1) Dying peacefully; 2) Not suffering; 3) Experiencing spiritual connection; and, 4) Making amends with significant others. Themes for a bad death were: 1) Experiencing death by accident or violence; 2) Prolonging life with life supports; 3) Becoming dependent while entering a dying trajectory; and, 4) Dying alone. <http://goo.gl/NcGySv>


N.B. Additional articles on end-of-life care for the homeless noted in Media Watch of 3 February 2014, #343 (p.4).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **THE LANCET NEUROLOGY** | Online – 3 March 2016 – ‘**My life, my death: My choice?**’ In September, 2015, the U.K. parliament voted against the assisted dying bill, with an overwhelming majority of 330 to 118. Assisted dying is a legal matter, first and foremost, as in the U.K. it is a criminal offence to encourage or assist suicide, punishable by up to 14 years imprisonment. It is also an ethical and moral issue that carries risks, many of which had been put forward in opposition to the bill – in particular, it could target the vulnerable, sending out the message that disability, or old age, are burdens on our society. <http://goo.gl/Gr3f9P>
- **MÈTODE SCIENCE STUDIES JOURNAL** | Online – Accessed 8 March 2016 – ‘**Analysis of health communication texts: U.K. press coverage of debates about assisted dying.**’ Conventionally, social researchers analyse media messages by reading text and coding it. This is time consuming and restricts many studies to small samples. Nowadays large amounts of text are available in electronic form, offering potential insights into the health messages they contain, but which appear daunting to the analyst with limited resources using conventional methods. <http://goo.gl/xZ8nKX>

Media Watch: Back Issues – <http://goo.gl/frPgZ5>



The screenshot shows the website for the International Palliative Care Resource Center (IPCRC.NET). The header includes navigation links: Home, About IPM, OIA, NCI, Partners, Contact, and Acknowledgements. Below the header, there is a section for 'GLOBAL PALLIATIVE CARE NEWS ARCHIVE' and 'MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE'. A sidebar on the right lists 'Media Watch Archives' with links for various periods: 2014, July - December; 2014, January - June; 2013, July - December; 2013, January - June; 2012, July - December; 2012, January - June; 2011, July - December; 2011, January - June; and Current. The main content area features a news item titled 'MW 452: Dying better, even if it means sooner' with a download link for the complete issue (PDF 275 KB). Below this, there is a snippet of text from a 'U.S. REPORT & WORLDS NEWS' article dated 29 February 2016, discussing the focus of care providers on delaying death for patients in their 80s, 90s, and 100s.

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/zJ7iOo>

IAHPC link updated 03.14.2016

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

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

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

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://goo.gl/XrhYCH>

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <http://goo.gl/AhlqvD>

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1l9K>

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

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