Media Watch...

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

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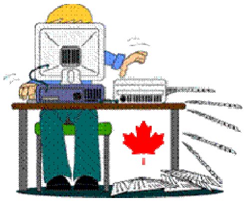


Compiled & Annotated by Barry R. Ashpole

"Hidden mourners" – Scroll down to Specialist Publications and 'Think adult – think child! Why should staff caring for dying adults ask what the death means for children in the family?' (p.9), in *British Medical Bulletin*.

Canada

Queen's University researcher seeks to improve end-of-life care

ONTARIO | *The Kingston Herald* – 17 August 2017 – Dr. Daren Heyland, a researcher at Queen's University and director of the Canadian Researchers at the End-of-Life Network (CARENET), has developed new quality measures he hopes will used to improve end-of-life care (EoLC) in Canada. These new measures came about from earlier research that showed a significant proportion of Canadians are unhappy or dissatisfied with their EoLC.[1] "Inadequate or poor communication and decision-making at the end of life (EoL) is a major source of dissatisfaction with EoLC," said Dr. Heyland... "It adds to the suffering that patients and families experience and has been identified as a high priority for improvement." A questionnaire was issued to patients and their family members at 12 hospitals [in Alberta, British Columbia, Manitoba and Ontario] by Dr. Heyland and his team, collecting their opinions about advance care planning and goals-of-care discussions. The project's goal was to use the survey feedback to begin monitoring and improving care by ensuring the system better meets their needs. The survey results gathered from 297 patients and 209 families revealed quality of EoL communication and decision making available to patients is low overall. https://goo.gl/SC6ejo

Specialist Publications

'Second medical opinions in end-of-life disputes in critical care: An ethics-based approach' (p.10), in *Healthcare Quarterly.*

'The delivery of palliative and end-of-life care in Ontario' (p.11), in *Healthcare Quarterly*.

'Public and professional insights on end-of-life care: Results of the 2016 Health Care in Canada Survey' (p.18), in *Healthcare Quarterly*.

1. 'Validation of quality indicators for end-of-life communication: Results of a multicentre survey, *Canadian Medical Association Journal*, 2017;189(30):e980-e989. [Noted in Media Watch 7 August 2017 (#524, p.9)] https://goo.gl/uAYSqk

Cancer lingo: How one person's thoughtful metaphor can be another's *cliché*

ONTARIO | CBC News (Toronto) – 13 August 2017 – Warrior metaphors – or whatever you want to call those cancer *clichés* – have been around for some time. But the language was thrust back into the public spotlight after the recent brain cancer diagnosis of U.S. Senator John McCain. On Twitter, well-wishers ... described the senator as a "brave fighter." On TV newscasts, reporters suggested that while McCain was in for a tough battle, his disease had a "worthy opponent." "Most of us are not real fans of using these battle metaphors," says Dr. Elie Isenberg-Grzeda, a psychiatrist at Toronto's Sunnybrook Health Sciences Centre. Warrior metaphors prevent a person with cancer from being honest with friends and family, he says. And the result is loneliness and isolation. https://goo.gl/kP12Wx

Noted in Media Watch 22 May 2017 (#513, p.1):

- *THE NATIONAL POST* | Online – 19 May 2017 – **'Learning to live with cancer.'** Framing cancer as a kind of war within our bodies can seriously harm a person's emotional psyche. "Who wants to go to war with themselves?" radiation oncologist Edward Halperin, of New York Medical College, writes...[1] "How is it ever helpful to think of oneself as a victim who was randomly attacked and now you're trying to kill your assailant in order to survive?" https://goo.gl/wJgXXA

1. 'Military metaphors and the consequences of the language of cancer,' *Practical Radiation Oncology*, 2017; 7(1):1-3. https://goo.gl/KJRZhr

U.S.A.

Medicare unveils "skeletal" site for hospice comparison shopping

KAISER HEALTH NEWS | Online – 18 August 2017 – Medicare launched a website aimed at helping families choose a hospice – but experts say it doesn't help very much. The Centers for Medicare & Medicaid Services this week released Hospice Compare, a consumer-focused website that lets families compare up to three hospice agencies at a time, among 3,876 nationwide.[1] Following similar websites for hospitals and nursing homes, the site aims to improve transparency and empower families to "take ownership of their health," according to a press release. Through the website, families can see how hospices performed in seven categories, including how many patients were screened for pain and breathing difficulties, and how many patients on opioids were offered treatment for constipation. But the measurements of quality, which are self-reported by hospices, have limited utility, some experts say. Over three-quarters of hospices scored at least 91% out of 100 on six of the seven categories, a recent paper found.[2] Because so many hospices reported high marks, there is "little room" for using these metrics to measure hospice quality, argued the authors... The Hospice Compare grades are based on hospices reporting whether they followed a specific process, such as screening for pain when the patient arrives. This type of metric may lead staff to just check a box to indicate they completed the desired process, resulting in high grades for everyone... https://goo.gl/HbENXG

Specialist Publications

'Hospice, she yelped: Examining the quantity and quality of decision support available to patient and families considering hospice' (p.14), in *Journal of Pain & Symptom Management.*

'Association between hospice spending on patient care and rates of hospitalization and Medicare expenditures of hospice enrollees' (p.14), in *Journal of Palliative Medicine.*

'Palliative care consults in U.S. nursing homes: Not just for the dying' (p.14), in *Journal of Palliative Medicine.*

1. 'Challenges of measuring quality of community-based programs for seriously ill individuals and their families,' *Health Affairs*, 2017;36(7):1227-1233. https://goo.gl/9iPGuG

N.B. The focus of this issue of *Health Affairs* is on advance illness and end-of-life care. [Noted in Media Watch 10 July 2017 (#520, p.10)] Journal contents page: https://goo.gl/jebK3j

Alex Hoover Act

Teen whose mom fought for medical directive dies

TEXAS | *The Decatur Daily* (Decatur, Alabama) – 16 August 2017 – Alex Hoover, whose mother Rene fought for her terminally ill son to attend East Limestone High School with directives about his medical care, died... He was 16. The bill named for Alex passed in the Alabama House, but died in the Senate on the final day of this year's legislative session. The legislation, called the Alex Hoover Act, had provided for portable medical orders to be created for a minor with a chronic or terminal illness and outlined expectations of care. It would have allowed the child to participate in school and other activities. The House bill passed at a time when the Athens teen's health condition had drastically declined... In 2015, Rene Hoover had asked Limestone County Schools to adhere to advance medical directives set up for Alex, whose terminal heart condition could cause him to go into cardiac arrest. She also asked that she be allowed to attend school with Alex, then 14, so she could make medical decisions on his behalf. She went through a lawyer to obtain an advance directive, but there is no law saying the school system must obey the directive. She wanted a do-not-resuscitate order for Alex, but was unable to obtain one because of his age and because it must be ordered by a doctor. School officials had said no federal or state policies were in place for school systems to follow regarding DNRs and advance directives for minors. https://goo.gl/eCxToB

N.B. Additional articles regarding Alex Hoover are noted in the 8 May 2017 issue of Media Watch (#511, p.2).

Noted in Media Watch 5 September 2016 (#478, p.17):

- *PEDIATRIC CLINICS OF NORTH AMERICA*, 2016;63(5):899-911. **'Integrating pediatric palliative care into the school and community.'** When a child has an out-of-hospital do-not-resuscitate order, heath care providers should partner with schools to provide support to the child and family, as well as to school professionals, to ensure a positive outcome for all parties. http://goo.gl/wpZI26

Related

- TEXAS | KCBD TV (Lubbock) – 16 August 2017 – **'Governor Abbott signs legislation reforming do-not-resuscitate orders in Texas.'** Governor Greg Abbott signed Senate Bill 11 to strengthen patient protections related to do-not resuscitate (DNR) orders. This bill closes a loophole in state law that permitted doctors to place DNR orders on patients without their consent. https://goo.gl/iPbihL

Tibetan Buddhism-based "compassion" training for doctors targets burnout

THE WASHINGTON POST | Online – 16 August 2017 – [Surgeon Carla] Haack represents a growing number of physicians experiencing job burnout, characterized by emotional exhaustion, feelings of cynicism and a low sense of personal accomplishment. A 2011 survey by the Mayo Clinic found that nearly half of physicians in the U.S. have at least one symptom of burnout, and the phenomenon is more common among doctors than other professions. A type of burnout called "compassion fatigue" often affects health-care professionals and can result in a loss of empathy for patients, emotional numbing and a sense of no control. This can have a detrimental effect on patient outcomes. Studies have found that higher levels of physician burnout correspond to more medical errors, which represent the third leading cause of death in the U.S. To combat physician burnout, some medical schools have launched programs to teach "soft skills" to better equip their doctors for today's stressful health-care environment. Learning compassion, empathy and resilience that speak to the human service challenges of the job have helped many individuals rediscover the meaning of medicine and why they became a doctor in the first place. https://goo.gl/nA2EEy

Cont.

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

- *JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS*, 2017;15(7):1905-1933. **'Prevalence of burnout in health professionals working in palliative care: A systematic review.'** More than ever, the current increasing need for palliative care (PC) leads to health professionals providing this type of care which further leads to multiple challenges, and stressful and demanding situations. The multiple challenges of working in PC put health professionals working in this context at the risk of burnout. https://goo.gl/2yFzFc

  N.B. Additional articles on clinician burnout in the context of hospice and palliative care are noted in this issue of Media Watch.

Noted in Media Watch 5 November 2012 (#278, p.10):

- *CONTEMPORARY BUDDHISM,* 2012;13(1):139-155. **'The *vihara* of compassion: An introduction to Buddhist care for the dying and bereaved in the modern world.'** As the [hospice] movement has grown, it has inspired Buddhists in Asia to rediscover and revive their own traditions around death and caring for the terminally ill and the bereaved that date back to the time of the Buddha. In Asia and the West as well, we are witnessing the work of several groups attempting to apply Buddhist teachings and practices in modern medical settings or develop new institutions for holistic care based in Buddhist values. https://goo.gl/tq5veh

End-of-life advice: More than 500,000 chat on Medicare's dime

KAISER HEALTH NEWS | Online – 14 August 2017 – In 2016, the first year health care providers were allowed to bill for the service [i.e., end-of-life consultation], nearly 575,000 Medicare beneficiaries took part in the conversations, new federal data ... show. Nearly 23,000 providers submitted about $93 million in charges, including more than $43 million covered by the federal program for seniors and the disabled. Use was much higher than expected, nearly double the 300,000 people the American Medical Association projected would receive the service in the first year. That's good news to proponents of the sessions, which focus on understanding and documenting treatment preferences for people nearing the end of their lives. Patients and, often, their families discuss with a doctor or other provider what kind of care they want if they're unable to make decisions themselves. Still, only a fraction of eligible Medicare providers – and patients – have used the benefit, which pays about $86 for the first 30-minute office visit and about $75 for additional sessions. Nationwide, slightly more than 1% of the more than 56 million Medicare beneficiaries enrolled at the end of 2016 received advance care planning talks, according to calculations by health policy analysts at Duke University.[1] https://goo.gl/ZJhnCx

Specialist Publications

'Getting it right at the end of life' (p.12), in *Journal of Family Practice.*

'Physician perceptions of barriers to advance care planning' (p.12), in *South Dakota Medicine.*

1. 'Death of outrage over talking about dying,' *BMJ Supportive & Palliative Care*, published online 2 February 2017. [Noted in Media Watch 6 February 2017 (#498, p.7)] https://goo.gl/mSuIGu

Noted in Media Watch 7 August 2017 (#424, p.3):

- *KAISER HEALTH NEWS* | Online – 1 August 2017 – **'Many still sidestep end-of-life care planning, study finds.'** Even though advance directives have been promoted for nearly 50 years, only about a third of U.S. adults have them, according to a recent study.[1] People with chronic illnesses were only slightly more likely than healthy individuals to document their wishes. https://goo.gl/MZaMLZ

  1. 'Approximately one in three U.S. adults completes any type of advance directive for end-of-life care,' *Health Affairs*, 2017;36(7):1244-1251. https://goo.gl/wZHzmG

Report explores Catholic perspectives on end-of-life care

THE PEW CHARITABLE TRUSTS | Online – 14 August 2017 – Religion plays a key role in addressing the spiritual, emotional, and psychological concerns faced by many patients and families around dying and the care they want near the end of life. Yet religious communities vary in their approach to the questions that people wrestle with when confronting a serious illness. The Center for Practical Bioethics ... engaged a group of two dozen Catholic educators and thought leaders from a variety of clinical, religious, and ethical perspectives to explore differences in understanding and applying church teachings regarding palliative care (PC) and advance care planning. The ensuing report,[1] reflects a robust discussion of church teachings on every individual's value and dignity and the moral considerations of burden and benefit around treatment. The report studies a Catholic's social responsibility to uphold the dignity of life, regardless of patient capacity and dependency, and the complex ethical issues affecting providers and stakeholders during shared decision-making. Significantly, the group agreed on the importance of PC... The group pointed to the need for overarching discussions of PC in a patient's first medical encounter during a serious illness, underpinning the idea that clinicians, spiritual leaders, and others in the health system should accompany patients and their families throughout their illnesses. https://goo.gl/suSxd4

Specialist Publications

'Distinctive factors affecting the legal context of end-of-life medical care for older persons' (p.18), in *Georgia State University Law Review*.

'The views of clergy regarding ethical controversies in care at the end of life' (p.18), in *Journal of Pain & Symptom Management*.

1. 'Pathways to Convergence,' The Pew Charitable Trusts, August 2017. https://goo.gl/AqwTWB

Noted in Media Watch 9 May 2016 (#461, p.2):

- *FORBES* | Online – 7 May 2016 – **'Health care denied at 550 hospitals because of Catholic doctrine.'** A new report finds that 1 in 6 hospitals in the U.S. are operated in accordance with Catholic religious rules, known as the Ethical & Religious Directives.[1] In Washington state, for example, data shows 40% of all hospital beds are in a Catholic hospital. There is no other option for care in entire regions. This is especially true in rural regions and it is frightening when the only access to health care is dictated by someone else's religious doctrine, rather than medical science. http://goo.gl/WLnSmM

    1. 'Health Care Denied,' American Civil Liberties Union, May 2016. https://goo.gl/o0FLMi

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- OREGON | *The Bulletin* (Bend) – 14 August 2017 – **'Rural Oregonians still face death with dignity barriers.'** Oregon's historic right-to-die law is almost elusive to those in rural areas. Of the 1,127 Oregonians who died using Death with Dignity medication between 1998 and 2016, 88 lived east of the Cascade Range... In rural pockets of the state there are no doctors willing to help within 100 miles... Most prescriptions are written in the Portland area. The effect of that is after being told they have six months or less to live, after making what could be the toughest choice of their lives, patients ... are forced to spend their remaining weeks or months searching for doctors willing to help them use Death with Dignity. https://goo.gl/oiT5VN

International

End-of-life care in Australia

New South Wales palliative care the subject of scathing auditor-general report

AUSTRALIA (New South Wales) | ABC News (Sydney) – 17 August 2017 – New South Wales (NSW) auditor-general Margaret Crawford has released a scathing report on palliative care (PC),[1] five months after some services in the Hunter New England region were described as being akin to those in the 1960s.[2] Ms. Crawford did not hold back in her report. "NSW Health's approach to planning and evaluating PC is not effectively co-ordinated," she said. "There is no overall policy framework for palliative and end-of-life care, nor is there comprehensive monitoring and reporting on services and outcomes." Crawford described services as being *ad hoc*, and said the health department's approach to planning and evaluating PC was not effectively coordinated. "NSW Health has a limited understanding of the quantity and quality of PC services across the state, which reduces its ability to plan for future demand and the workforce needed to deliver it," she said. "At the district level, planning is sometimes *ad hoc* and accountability for performance is unclear." https://goo.gl/o2Fq9k

1. 'Planning and evaluating palliative care services in NSW,' Auditor Office of New South Wales, August 2017. https://goo.gl/5uoxmH

2. 'Palliative care in regional New South Wales at 1960s standards, expert says,' ABC News, 6 March 2017. [Noted in Media Watch 13 March 2017 (#503, p.5)] https://goo.gl/OT82Ry

Noted in Media Watch 19 June 2017 (#517, p.5):

- AUSTRALIA (New South Wales) | ABC News (Sydney) – 12 June 2017 – **'Palliative care services in regional New South Wales to get a $100 million boost after outcry over system.'** The New South Wales Government has announced a record $100 million spend on palliative care services, with the focus on improving access for country families. The announcement follows protests and consultations about a lack of services in country New South Wales. The state's Health Minister Brad Hazzard said at the moment 70% of people who want to die at home do not get their wish. https://goo.gl/DeC5y6

Elder care in England

More than 70,000 extra care home places needed by 2025

U.K. (England) | *The Daily Telegraph* (London) – 16 August 2017 – More than 70,000 extra care home places will be needed by 2025, with pensioners now spending twice as long living without independence, a *Lancet* study suggests.[1] Women over the age of 65 can now expect to spend the last three years of their lives in a care home, or receiving help several times daily, the research shows. Two decades ago they could expect to spend the last 18 months of their lives in need of such help. And the average man will receive such care for the last two and a half years of his life – when 20 years earlier, they could expect to spend just over a year in need of such assistance. *The Lancet* study showed an urgent need for a substantial investment in services, with too many pensioners left living in fear that the costs would overwhelm them. The research ... said almost 190,000 new care home places will be needed by 2035 to accommodate soaring demand. https://goo.gl/QnrQUw

Specialist Publications

'The determinants of dying where we choose: An analysis of 'Coordinate My Care'' (p.8), in *Annals of Internal Medicine*.

1. 'Is late-life dependency increasing or not? A comparison of the cognitive function and ageing studies,' *The Lancet*, published online 15 August 2017. https://goo.gl/5ty6Bd

Cont.

Related

- U.K. (England) | *The Times* (London) – 14 August 2017 – **'Funding crisis leaves thousands of care homes facing collapse.'** One in six care home companies is in danger of insolvency, according to a report warning that successive rises in the living wage have driven up costs to the point where they may bankrupt a large part of the system.[1] About 420,000 people over the age of 65 are being looked after in Britain's 11,000 residential care homes, including 220,000 of the most vulnerable patients, who are in 4,700 nursing homes. https://goo.gl/vENpPf

    1. '16% of care homes at risk of failure,' Moore Stephens UK, August 2017. https://goo.gl/ykqKWb

N.B. Selected articles on end-of-life care in care and nursing homes noted in the 14 August 2017 issue of Media Watch (#525, pp. 7-8).

Medicine shortages in Venezuela: Dying in agony

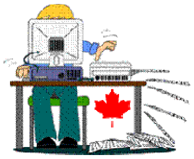
VENEZUELA | Human Rights Watch (Caracas) – 10 August 2017 – More than 23,000 Venezuelans die of cancer every year; about 80% develop moderate to severe pain in the last few months of life. Many others have cancers that may be treatable, but cause significant pain nonetheless. Before the current [political] crisis, Venezuela's health-care system boasted relatively strong palliative care (PC) services where morphine was readily available. With today's acute shortages, however, Dr. Patricia Bonilla, the founder of the Venezuelan Society of Palliative Medicine, says her life has turned into a constant hunt for medication so her patients do not have to suffer. She says she is endlessly trying to come up with new, creative ways to get her patients morphine. Apart from collecting medications from patients who have died, she advises families to go to Colombia or other countries in the region or even to buy them on the black market – a risky proposition as one has no way of knowing whether the medication is real. https://goo.gl/MtxAdn

N.B. Venezuela is ranked 45th, 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)] – http://goo.gl/nuPWIl; Sociedad Venezolana de Medicina Paliativa website – https://goo.gl/GnV4L5; 'Atlas de Cuidados Paliativos de Latinoamérica,' Asociación Latinoamericana de Cuidados Paliativos, 2012 (Spanish, Portuguese & English language versions available). [Noted in the 7 January 2013 issue of Media Watch (#287, p.8)] – https://goo.gl/jh1mAZ.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (New South Wales) | *The Sydney Morning Herald* – 14 August 2017 – **'Voluntary assisted dying back on the agenda.'** The debate over voluntary assisted dying has a renewed focus across the country. This month, bills to allow for medically assisted euthanasia will be introduced in the New South Wales and Victorian parliaments for a conscience vote. The states may become the first jurisdictions to legalise euthanasia in Australia since the Northern Territory's Rights of the Terminally Ill Act was overturned by the Federal Parliament in 1997, less than a year after it had commenced operation. https://goo.gl/NHz2ya



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

Specialist Publications

End-of-life care in England

The determinants of dying where we choose: An analysis of 'Coordinate My Care'

ANNALS OF INTERNAL MEDICINE | Online – 15 August 2017 – Enabling persons to die where they choose is considered a key indicator of quality in end-of-life care (EoLC). Most persons state that they would prefer to die at home or in a hospice, but more persons in England die in a hospital than in these settings (48% vs. 29%). Initially developed as the Electronic Palliative Care Co-ordination System for London, the 'Coordinate My Care' service enables persons to create a digital urgent care plan with their clinicians. It is accessible to all health and social care professionals involved in a patient's care. 'Coordinate My Care' is a unique data set that enables analysis of how prospective patient wishes and documented advance care plans influence EoLC. https://goo.gl/9HD2Rd

Opening the black box of peer review

CANADA | CBC News – 19 August 2017 – Imagine having all of your colleagues and all of your competitors looking over your shoulder at everything you do. And now imagine them pointing out everything you did wrong and sending you back to do it all over again. That's the basic premise of scientific peer review. Before a research paper is published in a scientific journal, several scientists examine the work to determine if the methods are sound and the conclusions are supported by the data. It's a much-heralded pillar of the scientific process. But the irony of peer review is that the process itself is never peer reviewed. David Moher, a senior scientist at the Ottawa Hospital Research Institute, called for the "black box" of peer review to be opened...[1] https://goo.gl/FF8Qr8

1. 'Promote scientific integrity via journal peer review data,' *Science*, 2017;357(6348):256-257.https://goo.gl/d1S64x

N.B. 'Coordinate My Care': https://goo.gl/kfcE1D

Noted in Media Watch 19 September 2016 (#480, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 September 2016 – **'Crash course in EPaCCS (Electronic Palliative Care Coordination Systems): 8 years of successes and failures in patient data sharing to learn from.'** Striking outcomes have been reported around EPaCCS, such as 77.8% of 'Coordinate My Care' patients dying in their preferred place. EPaCCS have, however, been extremely challenging to develop and implement, with many projects remaining continuously "under development" or folding. https://goo.gl/ao50pL

Related

- *BMC PALLIATIVE CARE* | Online – 16 August 2017 – **'Relatives' perceived quality of palliative care: Comparisons between care settings in which patients die.'** The quality of palliative care (PC) from the relatives' perspective is highest when the patient died at home or in a hospice. The experiences are less positive in particular for patients who died in hospital or in residential elderly care. This applies both to the general ratings given to care for the patient and their loved ones and to specific aspects of PC such as care for the psychosocial well-being of the patient and their loved ones, the attitudes to them, autonomy, information in the final week before death, and expertise. This can partly be ascribed to differences in the patient population, but it also seems partly to be genuinely related to the care setting itself. This is an argument for letting people die at home, if they so wish and where feasible, as far as possible. https://goo.gl/Rjrt1v

- *NURSING TIMES* | Online – 17 August 2017 – **'New specialist ambulance team to improve end of life care, especially for cancer patients.'** A specialist ambulance service, involving a new charity nurse post, is being established to help ensure the wishes of terminally ill patients in the North East are respected. The service has been created through a new partnership between Macmillan Cancer Support and North East Ambulance Service National Health Service Foundation Trust. The new team will be tasked with equipping ambulance staff with the specialist skills necessary to support terminally ill patients and the people around them... The team will also work with other healthcare and social care providers across the region to ensure patient care plans are fed into the system so their wishes can be respected throughout the process. It is hoped this service will mean more patients can continue to be cared for at home and prevent unnecessary admissions to hospital. https://goo.gl/i6RRjN

Think adult – think child! Why should staff caring for dying adults ask what the death means for children in the family?

BRITISH MEDICAL BULLETIN | Online – 10 August 2017 – Bereaved children and young people in the U.K. are "hidden mourners." Children experience grief that varies according to the circumstance of death and their cognitive ability. Voluntary organizations can be supportive, but provision is patchy and vulnerable to austerity. Areas of concern include adult-centric denial of the importance and long-term consequences of childhood grief, and uncertainty in how best to relate to bereaved children in faiths and in schools. Growing points include increased awareness of the immediate and long-term consequences of childhood bereavement and that even young children can experience loss through death. "Think adult – think child" means that all staff caring for dying adults should take responsibility for asking what the death means for the children in the family, with schools, primary care and faith organizations having protocols and expertise available to support grieving children; recent catastrophes expose need for agencies to have management plans that focus on vulnerable children and young people. https://goo.gl/W8ocRs

Noted in Media Watch 14 August 2017 (#525, p.8):

- *BMC PALLIATIVE CARE* | Online – 10 August 2017 – **'When a parent dies: A systematic review of the effects of support programs for parentally bereaved children and their caregivers.'** The studies reviewed revealed that when parents are supported, they can demonstrate an enhanced capacity to support their children. In three studies, the interventions were primarily directed at the bereaved children. The results showed positive between group effects both for children and caregivers in several areas, namely large effects for children's traumatic grief and parent's feelings of being supported; medium effects for parental warmth, positive parenting, parent's mental health, grief discussions in the family, and children's health. https://goo.gl/Vp1HdX

Sedation or the limits of palliative care: Ethical questions

ETHICS, MEDICINE & PUBLIC HEALTH | Online – 9 August 2017 – Sedation in palliative medicine continues to elicit questions that sometimes confound even the most experienced caregivers. The authors examine the boundaries between sedation and euthanasia. The ethics at stake in palliative sedation are almost systematically constructed with the perspective of polemic debates on euthanasia, especially in situations where sedation is wrongly qualified of "terminal." Perhaps out of fear for a possible confusion between sedation and euthanasia, current recommendations appear to be more of a formalization of the double-effect principle. But the double-effect principle and the principle of intentionality also have their limits. Sedation questions what might be deemed "ideal care," exposing the limits of palliative medicine: limits to defining a refractory symptom, limits to defining and relieving existential distress, limits to the ethical validity of prognosis, limits to the ideal of a "pacified" death, limits to maintaining a relational life until death. Sedation highlights a triple paradox: benevolence and autonomy vs. maintaining relationships, failure to relieve vs. idealized pacified death, and clinical uncertainty vs. ultimate medicalization of the end of life. To prevent the risks of underestimating distress or hastening to relieve, two qualities should be cultivated: availability as a necessary openness to otherness and vulnerability; and, resisting the temptation of reducing the ethical legitimacy of sedation to its decisional process. https://goo.gl/T9Bqtn

N.B. French language article. Additional articles on sedation in the context of end-of-life care are noted in the 17 July 2017 issue of Media Watch (#521, p.16).

Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.19.

End-of-life care in Germany

Palliative care for children with a yet undiagnosed syndrome

EUROPEAN JOURNAL OF PEDIATRICS | Online – 14 August 2017 – The number of children without a diagnosis in pediatric palliative home care and the process of decision-making in these children are widely unknown. In this single-center retrospective cohort study, between January 2013 and September 2016, 198 children and young adults were being cared for; 27 (13.6%) of these were without a clear diagnosis at the start of pediatric palliative home care. A definite diagnosis was ultimately achieved in three children. Despite the lack of a clear diagnosis (and thus prognosis), 13 (48.1%) parents faced with their critically ill and clinically deteriorating children decided in favor of a do not attempt resuscitation order. Children without a clear diagnosis are relatively common in pediatric palliative care and have – like all other patients – the right to receive optimized and symptom-adapted palliative care. Parents are less likely to choose treatment limitation for children who lack a definitive diagnosis. https://goo.gl/zuEpzp

Second medical opinions in end-of-life disputes in critical care: An ethics-based approach

HEALTHCARE QUARTERLY, 2017;20(2):23-26. Requests for a second medical opinion (SMO) by patients or substitute decision-makers (SDMs) can arise during end-of-life (EoL) disputes in critical care. Such disagreements between patients or SDMs and physicians often pertain to specific elements of the decision-making process related to withholding or withdrawing of life-sustaining treatments. When these disputes occur in the critical care setting in Canada, practicalities and policy barriers prevent an SDM from obtaining an SMO without support from healthcare providers; moreover, in a majority of these cases the SDM will require the facilitation of a physician who is often the same individual with whom they are in conflict. Institutional and a national society's policy statements propose SMOs as an important component of a conflict resolution process for EoL disputes... However, these policies do not provide specific guidance to physicians on how to fairly consider SMO requests. Given the vulnerable position of patients and their SDMs in the critical care context and in order to promote fairness, physicians should apply consistent standards in deciding whether to facilitate a request for an SMO. To guide physicians' decision-making and inform future policy development, the authors propose three ethical principles for considering SDM requests for an SMO in critical care at the EoL. https://goo.gl/6H8oLq

Related

- *BMC PALLIATIVE CARE* | Online – 14 August 2017 – **'Socio-cultural contexts of end-of-life conversations and decisions: Bereaved family cancer caregivers' retrospective co-constructions.'** This study shows the paradox of the critical role played by the family as "the central cultural and affective unit within which knowledge of terminal illness is processed and care for the dying performed" versus the ill-preparedness of family caregivers (and families) in dealing with end-of-life (EoL) issues. Findings from this study are relevant in informing palliative psychosocial interventions and specifically the EoL concerns, needs and decisions of cancer patients and their families. https://goo.gl/rYBjvo

- *HEALTH COMMUNICATION* | Online – 18 August 2017 – **'Care providers' integration of family requests in end-of-life communication: Understanding what to do and why to do it.'** End-of-life (EoL) situations are fraught with challenges for patients, family members, and individuals working at the patient's bedside. Care workers must address needs of the patient, as well as his or her distressed family members. This article is an investigation of care workers' experiences with EoL discussions when the family asks to "do everything." The article concludes with a discussion about how identifying EoL terms may be transformed to be more accessible for family members. https://goo.gl/bhhyji

End-of-life care in Canada

The delivery of palliative and end-of-life care in Ontario

HEALTHCARE QUARTERLY, 2017;20(2):6-9. Most Ontarians [i.e., patient population studied] received limited palliative and end-of-life care (EoLC) in the community, despite prior findings that many older adults with a terminal illness want to spend their last days at home. Overall, fewer than 1 in 5 received palliative home care and fewer than 1 in 10 received a palliative physician home visit in their last year of life. Rural and northern regions in Ontario have the lowest proportion of decedents who had received any palliative physician services, home care and inpatient care. Unfortunately, there is currently no central and systematic coordination of palliative care (PC) in the province, contributing to disproportionate delivery of services among Ontarians dying from different causes and across jurisdictions. There are many reasons that contribute to the observed low levels of PC delivery. First, PC may not be provided because of the unexpected or rapid nature of some deaths, although sudden deaths have been estimated to represent only 5% of all deaths in Canada... Second, some healthcare practitioners, patients and caregivers may not recognize or accept that a patient is nearing the end of life early enough to initiate PC. Third, one of the main limitations of the studies reviewed is that some palliative supports may not be coded in the health administrative databases, even when practitioners recognize that their patient is at the end of life and are providing services that are palliative in nature. Capturing the diversity in PC delivery models (e.g., variations in interdisciplinary PC) remains a challenge, and the true extent of palliative and EoLC delivery is difficult to define and capture using administrative data alone. https://goo.gl/dt7wym

Noted in Media Watch 4 July 2016 (#469, p.2):

- CANADA | Health Quality Ontario – 28 June 2016 – **'Ontarians are talking about end-of-life care, yet for many, palliative care may begin too late or not at all, new report finds.'** Almost 60% of people in Ontario who die receive palliative care (PC) services, according to a new report by Health Quality Ontario.[1] And among those who have a record of receiving PC, about half begin to receive it in their last month of life. http://goo.gl/4iQXTu

    1. 'Palliative Care at the End of Life,' Health Quality Ontario, June 2016. http://goo.gl/GW0Xh9

Noted in Media Watch, 14 March 2016 (#453, p.2):

- CANADA | *The Ottawa Citizen* – 11 March 2016 – **'Numerous gaps in Ontario's system for palliative care, report finds.'** 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] 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

Intermountain Heart Institute, Salt Lake City, Utah

Palliative care use in hospitalized patients with heart failure: Low and late

JOURNAL OF CARDIAC FAILURE, 2017;23(8):S55. Given high morbidity and mortality in heart failure (HF), the integration of palliative care (PC) is suggested along the disease trajectory. The timing and use of PC during a HF hospitalization, however, is unclear. Therefore this analysis was completed from a large hospital system to characterize mortality trends in patients hospitalized with HF in relation to the use of PC services. From January 2015 to December 2016, 3,119 hospitalizations were analyzed across Intermountain's four largest hospitals... The use of PC in hospitalized HF patients was low, often occurring late in patients with the highest acuity. Recognizing clinical factors that add to the risk of mortality may help alert clinicians to involve PC. In keeping with national HF guidelines, strategies to partner with PC colleagues earlier in the HF trajectory are needed. Whether the timely use of PC will positively impact HF quality measures needs further study. https://goo.gl/bxcdQ3

Cont.

Noted in Media Watch 24 July 2017 (#522, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 21 July 2017 – **'Should heart failure be regarded as a terminal illness requiring palliative care? A study of heart failure patients', carers' and clinicians' understanding of heart failure prognosis and its management.'** This is the first study exploring the experiences of prognostic communication at all stages of heart failure (HF). Overall, the majority of participants rejected notions of HF as a terminal illness in favour of a focus on day-to-day management and maintenance, despite obvious deterioration in disease stage and needs over time. Clinicians revealed frustration about the uncertain nature of HF prognosis, leading to difficulties in planning. https://goo.gl/Jzfyoc

  N.B. Additional articles on end-of-life care for people living with heart failure are noted in this issue of Media Watch.

Advance care planning

Getting it right at the end of life

JOURNAL OF FAMILY PRACTICE, 2017;66(8):486. Although the concept of the living will was first proposed in 1969, the idea caught on slowly. In fact, the first scholarly article discussing the topic didn't appear until 16 years later. In contrast, an informal search of PubMed reveals that at least 38 articles on advance directives and end-of-life (EoL) care have been published during the first seven months of 2017. And a feature article in this month's issue [of this journal] ... makes one more.[1] Why is there such strong interest now in an issue that seldom arose when I began practice in 1978? More complex, less personalized medicine. As medical care has become more sophisticated, there is a great deal more we can do to keep people alive as they approach the EoL, and a great many more decisions to be made. Additionally, people are much less likely today to be cared for in their dying days by a family physician who knows them, their wishes, and their family well. In my early years in small-town practice, I was present when my patients were dying, and I usually knew their family members. Family meetings were easy to arrange, and we quickly came to a consensus about what to do and what not to do. We cared for our patients in the office, nursing home, and hospital. Now, most dying hospitalized patients are cared for by hospitalists who may be meeting the patient for the first time. https://goo.gl/CbPrxv

1. 'Advance care planning: Making it easier for patients (and you),' *Journal of Family Practice*, 2017; 66(8):487-491. https://goo.gl/Yfc3cG

N.B. Click on pdf icon to access full text.

Related

- *SOUTH DAKOTA MEDICINE*, 2017;70(7):303-309. **'Physician perceptions of barriers to advance care planning.'** Despite the benefits of directed end-of-life discussions, a variety of barriers including discomfort with the topic, physician ideology, lack of time and reimbursement, delaying discussions, and lack of training impede physicians from facilitating these crucial conversations with their patients. Physicians continue to face barriers to advance care planning as well as struggle with additional challenges such as difficulty with families, lack of patient education, inconsistencies and accessibility of advance directive documents, and lack of physician-physician communication or agreement in care. https://goo.gl/UyZUCD

Palliative care in special settings of cancer care

JOURNAL OF ONCOLOGY PRACTICE | Online – 16 August 2017 – Tribalism is a bold word that summarizes the behaviour of people who identify themselves as part of a group. Oncology as a whole is a tribe with its own customs, language, and conventions. Within oncology, surgical, radiation, medical, gynecologic, malignant hematologic, transplantation, and pediatric fields are distinct tribes with distinctive rites and rituals of usual behavior that are carried out in special settings. Successful integration of palliative care (PC) requires a keen and unabashed recognition of this. Most important ... is language. The prolonged training of oncologists of any stripe gives them a unique language. When someone in PC does not know how to "speak cancer," he or she is frequently shunned, denigrated, and not brought into the treatment team. Although those without oncology backgrounds can provide excellent PC for patients with cancer, if they do not understand the language and/or work to learn it, the wonderful alchemy of interdisciplinary teamwork will not happen. https://goo.gl/1yAUws

Unfinished business in families of terminally ill with cancer patients

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 12 August 2017 – Questionnaires were sent to 967 families and 73.0% responded. In total, 26% of families had some unfinished business, with improvement of the patient-family relationship being a common type of unfinished business. Families with unfinished business had significantly higher depression and grief scores after bereavement compared with those without. Factors that influenced the presence/absence of unfinished business were preparedness for the patient's death; discussion between the patient and family about the disease trajectory and way to spend daily life; good family-patient relationship; and, family and healthcare professionals considering together the appropriate timing to accomplish the family's wishes. Healthcare professionals should coordinate the appropriate timing for what the family wishes to do, with consideration of family dynamics including the family's preparedness, communication pattern, and relationships. https://goo.gl/X3J82k

Noted in Media Watch 15 June 2015 (#414, p.11):

- *DEATH STUDIES* | Online – 9 June 2015 – **'Unfinished business in bereavement.'** Unfinished business (e.g., incomplete, unexpressed or unresolved relationship issues with the deceased) is frequently discussed as a risk factor for chronic and severe grief reactions. This study aimed to address a gap in the literature by examining the presence and severity of unfinished business as well as common themes of unfinished business reported in open-ended qualitative narratives among a sample of 224 bereaved individuals. http://www.ncbi.nlm.nih.gov/pubmed/26057117

Noted in Media Watch 11 August 2014 (#370, p.11):

- *INTERNATIONAL JOURNAL OF PSYCHOTHERAPY*, 2014;18(2):72-79. **'The truth shall set you free: Saying an honest "goodbye" before a loved-one's death.'** This article reviews some of the relevant literature, defines the premise of "unfinished business," describes the therapeutic benefits of fantasy, and provides a case example using the "empty chair" method. The psychotherapy described is about creating an opportunity for the expression of feelings, making interpersonal contact, and "truth telling" before the other person dies. http://goo.gl/1QZOkv

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

Standardization and scaling of a community-based palliative care model

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 August 2017 – Although limited, the descriptions of community-based palliative care (CBPC) demonstrates variability in team structures, eligibility, and standardization across care settings. In 2014, Four Seasons Compassion for Life, a nonprofit hospice and palliative care (PC) organization in Western North Carolina (WNC), was awarded a Centers for Medicare & Medicaid Services Health Care Innovation (CMMI) Award to expand upon their existing innovative

Cont.

model to implement, evaluate, and demonstrate CBPC in the U.S. The objective of this article is to describe the processes and challenges of scaling and standardizing the CBPC model. The CBPC model was scaled across numerous counties in WNC and Upstate South Carolina. Over the first two years of the project, scaling occurred into 21 counties with the addition of 2 large hospitals, 52 nursing facilities, and 2 new clinics. To improve efficiency and effectiveness, a palliative care (PC) screening referral guide and a risk stratification approach were developed and implemented. Care processes, including patient referral and initial visit, were mapped. https://goo.gl/RpyPpR

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 14 August 2017 – **'Hospice, she yelped: Examining the quantity and quality of decision support available to patient and families considering hospice.'** An environmental scan identified 7 patient decision aids (PtDAs) that included hospice. No PtDAs were designed primarily around hospice; rather, hospice was referenced under the umbrella of another treatment option. A layperson search identified information distinct from the scan; no participant accessed any of the above 7 PtDAs. Many found the available online material confusing and biased, while failing to provide clear information on cost and lacking desired patient and caregiver testimonials. https://goo.gl/iYkNzN

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 August 2017 – **'Association between hospice spending on patient care and rates of hospitalization and Medicare expenditures of hospice enrollees.'** Care at the end of life is increasingly fragmented and is characterized by multiple hospitalizations, even among patients enrolled with hospice. In this longitudinal, observational cohort study patients cared for by hospices with lower direct patient care costs had higher hospitalization rates and were over-represented by for-profit hospices. Greater investment by hospices in direct patient care may help Centers for Medicare & Medicaid Services avoid high-cost hospital care for patients at the end of life. https://goo.gl/WcDmXP

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 August 2017 – **'Palliative care consults in U.S. nursing homes: Not just for the dying.'** In this longitudinal study, 4% of all nursing home (NH) residents received a palliative care (PC) consult during the study period. Two-thirds had short NH stays, and 81% of short- and 27% of long-stay consult recipients were on the Medicare skilled nursing facility (SNF) benefit at the time of initial consult. Short- and long-stay NH residents with PC consults differed not only, in many respects, from NH residents generally, but also from each other. Despite these differences, half of short-stay and 57% of long-stay residents were alive six months after initial consults. The high rates of SNF care and six-month survival among NH recipients of PC consults demonstrate the utility of these consults before Medicare hospice eligibility or use. https://goo.gl/fNE6cX

Spiritual care in the ICU: Perspectives of Dutch intensivists, ICU nurses, and spiritual caregivers

JOURNAL OF RELIGION & HEALTH | Online – 11 August 2017 – This study shows that spiritual care (SC) is not yet an integrated part of daily ICU care at a national level, despite the finding that the majority of intensivists, ICU nurses, and spiritual caregivers think SC contributes positively to the well-being of patients and relatives in the ICU. Additional findings included other similarities, but also differences in experiences with SC in the ICU from the perspectives of health care workers (HCW) and spiritual caregivers, and barriers that both HCW and spiritual caregivers encounter in ICU care. Moreover, this study points toward improvement of internal communication and interdisciplinary collaboration, expansion of knowledge of SC provision, and provision of evidence-based SC practice. https://goo.gl/o7jsjQ

Noted in Media Watch 13 February 2017 (#499, p.10):

- *DIMENSIONS OF CRITICAL CARE NURSING*, 2017;36(2):110-115. **'Creating a sacred space in the intensive care unit at the end of life.'** Critically ill patients and their families identify significant unmet spiritual, environmental, and communication needs. Although the Society of Critical Care Medicine recommends that the spiritual needs of critically ill patients be addressed by the health care team and be incorporated in patients' plans of care, spiritual concerns are infrequently addressed during goals-of-care discussions. https://goo.gl/LRAJ5L

Multiple sclerosis

Whose preferences matter? A patient-centered approach for eliciting treatment goals

MEDICAL DECISION MAKING | Online – 14 August 2017 – The authors sought to develop a patient-centered approach to elicit and compare the treatment goals of patients with multiple sclerosis and healthcare providers (HCPs). They conducted five nominal group technique meetings which yielded 34 unique patient-generated treatment goals and 31 unique HCP-generated goals. There were differences between patients and HCPs in the goals generated and how they were clustered. Patients' goals tended to focus on the impact of specific symptoms on their day-to-day lives, whereas providers' goals focused on slowing down the course of disease progression. Differences between the treatment goals of patients and HCPs underscore the limitations of using HCP- or investigator-identified goals. This new adaptation of cognitive mapping is a patient-centered approach that can be used to generate and organize the outcomes and attributes for values clarification exercises while minimizing investigator bias and maximizing relevance to patients. https://goo.gl/gaWHNC

N.B. Selected articles on palliative care for people living with multiple sclerosis are noted in the 17 October 2016 issue of Media Watch (#483, p.12).

Protecting me from my directive: Ensuring appropriate safeguards for advance directives in dementia

MEDICAL LAW REVIEW | Online – 16 August 2017 – With one in six people over 80 now suffering from dementia, advance directives (ADs) provide an important means of empowerment. Upholding directives in the context of dementia, however, raises extra challenges, given the potential for the directive to conflict with an assessment of what is in the person's current best interests. Given the profound harm that tying a person with dementia to their previous wishes can do, it is essential that we have sufficient safeguards in place to ensure that we only uphold such directives where we can be sure they are truly autonomous and are intended to apply to the situation at hand – safeguards which are at present, severely lacking. This article considers various mechanisms by which safeguards can be built into the legal regime to ensure that the original decision is autonomous, including making it mandatory for the person to undergo a consultation with a healthcare professional, which would involve a contemporaneous capacity assessment. Clinicians must also be confident that the directive applies to the situation at hand. Introducing formalities, including a standardised (though not mandatory) *proforma*, may help to enhance specificity about when the directive is triggered, and to what treatments it relates, to enable clinicians to better assess the directive's applicability. A national registry for ADs might also be beneficial. It is argued that health care professionals will have to play a much greater role in the drafting and registering of ADs, if we are to feel comfortable in upholding them. https://goo.gl/HJE4vS

Noted in Media Watch 10 July 2017 (#520, p.6):

- *AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS*, 2017;19(7):637-639. **'Dementia, decision making, and quality of life.'** Evidence suggests that many people with dementia, even those with more advanced disease, can still articulate their values, preferences, and choices in a reliable manner. Indeed, people with dementia maintain a strong desire to remain central in decision-making processes that directly impact their lives. Consequently, it is an ethical priority in the care of people with dementia to maximize the likelihood that they will have opportunities to live lives reflective of their values and maintain active, central roles in decision making. https://goo.gl/wTYkrG

N.B. Selected articles on end-of-life care for people living with Alzheimer's and other forms of dementia are noted in this issue of Media Watch.

Big Data analysis to improve care for people living with serious illness:
The potential to use new emerging technology in palliative care

PALLIATIVE MEDICINE | Online – 14 August 2017 – Healthcare professionals are generally unaware of how Big Data can be used to improve palliative care delivery. Furthermore, there is a lack of collaborative multi-professional groups with expertise in key areas (such as information technology, clinical practice, computer science, economics, statistics, and research methods). A lack of expertise in the development, maintenance and analysis of electronic health record systems may prevent adequate design of systems for the user. This may limit the quality of data collection and extraction (necessary for meaningful data analysis). Engagement with healthcare professionals is essential to support the design of digital systems that are necessary to improve the ability of clinical staff to work effectively. Additionally, data analysts are needed to make sense of the data generated by this process. Therefore, in order to realise the potential of Big Data, it is important to develop multi-professional groups with the expertise to use data meaningfully, to influence healthcare policy and clinical care delivery. https://goo.gl/KrK6Q4

Related

- *JOURNAL OF PATIENT CENTERED RESEARCH & REVIEWS*, 2017;4(3). **'Development of an algorithm to prospectively identify palliative care-eligible patients from the electronic health record.'** For referral-based health care programs, enrollment is usually triggered by a negative health event. This can mean that referral occurs late in the course of illness, even if patients would have benefited from earlier enrollment. In addition, a referral-based model gives little information about the total number of patients in need and provides no opportunity for outreach to better serve potentially eligible patients. https://goo.gl/jZPvrH

Noted in Media Watch 1 May 207 (#510, p.11):

- *INTERNATIONAL JOURNAL OF POPULATION DATA SCIENCE* | Online – 18 April 2017 – **'How different administrative databases change the size of a potential palliative care population.'** The use of different data sources to identify conditions that might benefit from palliative care will result in differing frequency of conditions and age and sex distribution of the population. This is a result of many people having multiple conditions and the method in which these are recorded in different data sources. It is important to be aware of the characteristics of the individual data sources when the data are used for health service planning. https://goo.gl/TS7g09

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https://goo.gl/diYn7i

End-of-life care in France

Prevalence and characteristics of prisoners requiring end-of-life care: A prospective national survey

PALLIATIVE MEDICINE | Online – 8 August 2017 – Overall, France has been reluctant to promote palliative care (PC) units in the prison sector, probably because terminally ill prisoners are supposed to be released, given that the law provides for this option. Prison palliative and hospice care units have been created in the U.S. and the U.K., and many promising practices have already been proposed, such as the use of peer volunteers, multi-disciplinary teams, special health units inside the prison, staff training, and partnerships with community hospices. Nevertheless, figures are not easily available to plan for resources. This study contributes to providing important data regarding end-of-life care (EoLC) in prisons in France and could serve as an example for other countries, although the methodology would need to be adapted to the context and legislation in other countries. Although the law allows for compassionate release, there are more ill prisoners requiring EoLC in jail than expected. Some should remain in prison regardless, particularly those whose only social ties are in prison, or those with a high risk of criminal reoffending. Knowledge of the profile of prisoners (medical, social, and juris-dictional) and the estimated prevalence of ill prisoners requiring PC could help define health-care needs for dying prisoners in agreement with humanitarian values and the Right to Health & Medical Care promulgated by the European Commission of Human Rights and the U.N. Bill of Human Rights. This is the first national study to focus on prisoners requiring EoLC in France. https://goo.gl/5pa3Jh

Palliative Care Network Community

Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (updated 31 July 2017) can be downloaded/viewed at: http://goo.gl/ZpEJyQ

Related

- *JOURNAL OF CORRECTIONAL HEALTH CARE* | Online – Accessed 13 August 2017 – **'The collision of inmate and patient: End-of-life issues in French prisons.'** This article highlights the realities regarding inmates at the end of life (EoL), putting into perspective the viewpoints of the sick prisoners with those of the health and correctional professionals accompanying them. The challenge is to identify potential barriers to palliative care (PC) for inmates in order to consider possible improvements. The study results reveal that EoL inmates were not fully considered as patients and did not benefit from a comprehensive PC approach. For most dying inmates, and according to many health professionals, compassionate release on medical grounds remains the best approach to deal with EoL issues. https://goo.gl/2LG5Xj

Perspectives of patients, close relatives, nurses, and physicians on end-of-life medication management

PALLIATIVE & SUPPORTIVE CARE | Online – 14 August 2017 – Five themes covering 18 categories were identified in this multi-center study: 1) Priorities in end-of-life (EoL) care, such as symptom management and maintaining hope; 2) Appropriate medication use, with attention to unnecessary medication and deprescription barriers; 3) Roles in decision making, including physicians in the lead, relatives' advocacy, and pharmacists as suppliers; 4) Organization and communication (e.g., transparency of tasks and EoL conversations); and, 5) Prerequisites about professional competence, accessibility and quality of medical records, and financial awareness. Patients, relatives, nurses, specialists, and GPs varied in their opinions about these themes. This study adds to our understanding of the complex practice of EoL medication management. It provides knowledge about the diversity of the perspectives of patients, close relatives, nurses, and physicians regarding beliefs, attitudes, knowledge, skills, behavior, work setting, the health system, and cultural factors related to the matter. https://goo.gl/aioAch

N.B. Additional articles on managing end-of-life medications, particularly in the context of home palliative care, are noted in the 19 June 2017 issue of Media Watch (#517, pp. 12-13).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *GEORGIA STATE UNIVERSITY LAW REVIEW* | Online – Accessed 15 August 2017 – **'Distinctive factors affecting the legal context of end-of-life medical care for older persons.'** Current legal regulation of medical care for individuals approaching the end of life (EoL) in the U.S. is predicated essentially on a factual model emanating from a series of high-profile judicial opinions concerning the rights of adults who become either permanently unconscious or are clearly going to die soon with or without aggressive attempts of curative therapy. For jurisprudential pioneers such as Karen Quinlan, Nancy Cruzan, Claire Conroy, Nancy Jobes and, more recently, Theresa Schiavo, the questions presented for adjudication revolved around the discrete withholding or withdrawal of specific life-sustaining medical interventions such as artificial feeding, respirators, dialysis, cardiopulmonary resuscitation, or antibiotics. In many of today's difficult medical situations, however, this prevailing, dramatic pull-the-plug EoL paradigm does not fit very neatly. https://goo.gl/5STCRW

- *HEALTHCARE QUARTERLY*, 2017;20(2):18-22. **'Public and professional insights on end-of-life care: Results of the 2016 Health Care in Canada Survey.'** A new dimension has been added to Canadian Medicare – exemption from prosecution for physicians, nurse practitioners and assistants providing medical assistance in dying for competent and informed adult patients with a grievous and irremediable medical condition causing intolerable physical or psychological suffering, irreversible decline in capabilities and reasonably foreseeable natural death. Among the public, enhanced pain management, hospice/palliative care and home/family care were all supported at, or above, the 80th percentile; medically assisted death was supported by 70%. Among all professionals, hospice/palliative care, pain management and home care garnered >90% support; support for medically assisted death ranged from 58% (physicians) to 79% (allied professionals). https://goo.gl/wYvtJY

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 14 August 2017 – **'The views of clergy regarding ethical controversies in care at the end of life.'** While religion often informs ethical judgments, little is known about the views of American clergy regarding controversial end-of-life (EoL) ethical issues, including allowing to die and physician-aid in dying or physician-assisted suicide (PAD/PAS). Survey respondents agreed that there are circumstances in which the terminally ill should be "allowed to die" (80%). A minority agreed that PAD/PAS was morally (28%) or legally (22%) acceptable. Mainline/Liberal Christian clergy were more likely to approve of the morality (56%) and legality (47%) of PAD/PAS, in contrast to all other clergy groups (6%-17%). Greater EoL medical knowledge was associated with moral disapproval of PAD/PAS... Those reporting distrust in healthcare were less likely to oppose legalization of PAD/PAS... Religious beliefs associated with disapproval of PAD/PAS, included "life's value is not tied to the patient's quality of life" ... and, "only God numbers our days"... Respectful discussion in public discourse should consider rather than ignore underlying religious reasons informing EoL controversies. https://goo.gl/DRmUL2

- *THE SCIENTIST* | Online – 17 August 2017 – **'Interactive infographic: The global business of dying.'** Although in many parts of the world, the rules governing the legality of assisting in another person's death are murky at best, some countries have passed legislation that explicitly allows doctors to aid in ending the lives of their patients – either by prescription of a lethal dose of drugs such as barbiturates (generally termed medical aid-in-dying in the U.S.) or by a clinician-administered lethal injection (often called euthanasia). In most, but not all, of these countries, the patient must be an adult, reside in the country where they receive end-of-life care, and have an incurable medical condition that causes them suffering. https://goo.gl/YfKXWX

  Related

  - *THE SCIENTIST* | Online – 17 August 2017 – **'Accessing drugs for medical aid-in-dying.'** A fraught market for the barbiturates prescribed to terminally ill patients who choose to end their lives has physicians turning to options outside big pharma. https://goo.gl/o6GEWQ

Worth Repeating

Interpreting educational evidence for practice: Are autopsies a missed educational opportunity to learn core palliative care principles?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 December 2014 – U.K. policy requires undergraduate medical curricula to equip students to care for dying patients. The educational potential of autopsy attendance during authentic early experience to learn about the social context of death and dying has not been fully explored. The author: 1) Explores how meaning is created from autopsies in authentic early experience; 2) Compares views of students, curriculum designers and pathology supervisors; and, 3) Identifies actual/potential learning about death and dying. The autopsy enabled students to learn about death and dying in a social context. Variance between groups in perceptions of autopsy experiences may reduce educational value. Autopsies were considered by students to be opportunities for "meeting" real people, albeit dead ones, and learning from them. Tensions between lay and medical perspectives influenced learning. Increasing communication and collaboration between medical school curriculum designers and disciplines such as palliative medicine as well as pathology could address concerns regarding student/doctor competencies to deal with death and dying. Further research is needed to evaluate changes in curriculum design and to establish if similar concerns are found in other settings. [Noted in Media Watch 17 December 2012 (#284, p.7)] https://goo.gl/AGWgYV

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/nZMuK7

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 'Media Watch by Barry Ashpole']

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: https://goo.gl/lXO4mD

SINGAPORE | Centre for Biomedical Ethics (CENTRES): https://goo.gl/JL3j3C

Canada

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

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

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

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

Europe

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

HUNGARY | Magyar Hospice Alapítvány: http://goo.gl/5d1l9K

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

Media Watch: Editorial Practice

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

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

Something Missed or Overlooked?

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

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