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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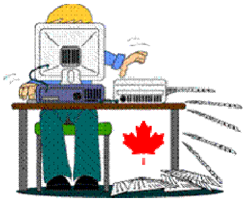

Compiled & Annotated by Barry R. Ashpole

Enhancing communications skills: Scroll down to Specialist Publications and 'Nursing support of home hospice caregivers on the day of patient death' (p.12), in *Oncology Nursing Forum*.

Canada

Scary cancer statistic is not personal

CBC NEWS | Online – 24 June 2017 – There's a way to cut cancer rates by 50%. Why wasn't that the Canadian Cancer Society headline? It's a question we asked this week with the release of the 2017 Canadian cancer statistics report.[1] It's an annual event the media treats as "news" even though cancer statistics change very little from one year to the next. That means much depends on the headline. Every year the Society chooses what they want the story to be. Then they highlight their chosen angle in the accompanying news release.[2] They send the media materials to reporters days in advance and insist that nothing be published until they say it's OK. This year, they set their embargo for Tuesday, 20 June, at exactly 3:01 a.m. ET. So on Tuesday Canadians woke up to the alarming news that nearly one in two of them will get cancer. It's a headline that has the potential to be gravely misleading if anyone assumes they personally have a 50/50 chance of getting cancer. There was a reassuring caveat, buried deep in the report, that "the estimated probabilities are for the general Canadian population and should not be interpreted as an individual's risk." The other problem with the headline is that it's not new. For years, cancer epidemiologists have estimated the lifetime probability of cancer at around 50%. The only difference this year was the way the statisticians crunched their numbers. It's a tweak that changed the incidence rate by a fraction of a percentage point over last year. The scary headline also misses the good news in this report. https://goo.gl/VSr24G

Extract from Canadian Cancer Society report

The primary goals of palliative care (PC) are to manage pain and symptoms, provide psychosocial, emotional and spiritual support, and enhance quality of life. Although it is often thought of as treatment given at the end of life, PC can be delivered progressively throughout the course of the disease. A comprehensive approach to PC can improve the quality of life for people with cancer and their caregiver, and increase the likelihood people with cancer die in the setting of their choice. PC can also reduce time spent in intensive care units and reduce hospital re-admissions.

1. 'Canadian Cancer Statistics, 2017,' Canadian Cancer Society, June 2017. https://goo.gl/mKxtp5
2. 'Nearly 1 in 2 Canadians expected to get cancer: Report,' Canadian Cancer Society, June 2017. https://goo.gl/jKPNfv

Assisted (or facilitated) death

Vancouver Island Health opts to move Comox hospice beds to secular facility

BRITISH COLUMBIA | *The Times Colonist* (Victoria) – 23 June 2017 – Comox Valley residents who want access to medical assistance in dying are celebrating a decision to move the region's hospice beds into a secular space. The Comox Valley's four hospice beds are hosted in Hospice at the Views, which is run by St. Joseph's General Hospital. As a faith-based facility, it does not allow assisted dying. Those four beds, as well as two new ones, will be located together in a different location, said Elin Bjarnason, executive lead for end-of-life and medical quality at Vancouver Island Health. "We've been considering for some time the location. And, in conversation with St. Joseph's around their contract for the four hospice beds, we've come to an agreement that we will relocate those four hospice beds," she said. Bjarnason said she hopes a decision is made by mid-October, so the beds can be in place in April 2018. In April [2017], 88 Comox Valley physicians signed a letter to Vancouver Island Health that called for a non-religious site to host hospice beds. Only 11.5% of Comox Valley residents identified themselves as Catholic in the 2011 census. https://goo.gl/se2Jv6

Noted in Media Watch 24 April 2017, #509 (p.2):

- BRITISH COLUMBIA | *The Times Colonist* (Victoria) – 18 April 2017 – **'Expansion brings assisted-dying issue to fore.'** The planned expansion of the Comox Valley's hospice beds has sparked a heated debate about medical assistance in dying (MAiD), which isn't allowed at the Catholic hospital that runs the facility. MAiD is not provided at Hospice at The Views, which is co-owned and operated by St. Joseph's General Hospital. The Comox Valley is one of the only hospices on the Island where you can't access MAiD, said Terri Odeneal, executive director for the Comox Valley Hospice Society. "We believe that hospice palliative care in the Comox Valley should not be different than other communities on Vancouver Island, now that MAiD is legal throughout the country," Odeneal said. St. Joseph's declined to provide the procedure, claiming freedom of conscience and religion. https://goo.gl/MhsZHo

Related

- MANITOBA | *The Winnipeg Free Press* – 21 June 2017 – **'The beliefs of some, paid for by all.'** Questions of doing harm, doing good and causing harm while in the pursuit of a greater good are front and centre this week at St. Boniface Hospital (SBH), where administrators, board members, health-care professionals and patients are grappling with big questions related to the issue of assisted dying. The hospital landed in a political and public-relations firestorm this week after the Catholic Health Corporation of Manitoba – which controls SBH – took the controversial step of reconfiguring the hospital's board after the passage last month of a motion to allow for medically assisted death under "rare circumstances." The corporation responded by adding 10 new members to SBH's board, forcing a re-vote that effectively bans assisted dying at the hospital – which, ironically, is the province's primary palliative care centre. https://goo.gl/C9GyCM

- ONTARIO | *The National Post* – 21 June 2017 – **'Doctors who conscientiously object to providing euthanasia referrals should not be forced to do so.'** From 12-15 June, the Ontario Superior Court of Justice heard legal arguments relating to conscience rights for doctors in Ontario. Five doctors and three physicians' organizations want the court to declare portions of policies created by the College of Physicians & Surgeons of Ontario (CPSO) a violation of doctors' rights enshrined in the Charter. A decision is expected later this year. CPSO, the respondent in the case, has stated they may suspend or sanction a doctor that refuses to participate in an assisted suicide, which they ... call "medical aid in dying" (MAiD). Euthanasiasts prefer the euphemism because "aid in dying" sounds softer and gentler than "kill." But the true definition of MAiD is palliative care, whose future as a medical discipline has been thrown into uncertainty by the CPSO's bullish stance on assisted suicide. https://goo.gl/XJEVJc

U.S.A.

Solutions remain elusive as elderly prisoners grow in number

MISSOURI | *The Missourian* (Columbia) – 24 June 2017 – In Missouri, the number of people age 50 and older who are in prison is increasing at 11 times the rate of the prison population overall. Prisoner advocates, prosecutors and state agencies have differing ideas of how to address the increase and its impact on the prison system. No comprehensive state-wide policy exists. In short, there is no consensus on how long it makes sense to keep geriatric prisoners behind bars. The oldest currently incarcerated person in Missouri is 92 years old, according to the Department of Corrections prisoner database. According to annual profiles of the prison population published by the Department of Corrections, Missouri's 50-and-older prison population has nearly doubled since 2005, compared to a less-than-10% increase in the total prison population during the same time. Missouri is one of 31 states nationwide to provide hospice care, care for chronic illnesses and long-term nursing home care on-site in their prisons. https://goo.gl/8p8JcR

International

'Prisons taking role of care homes and hospices as older population soars' (p.4), in *The Guardian.*

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report is posted on the Palliative Care Community Network website at: http://goo.gl/ZpEJyQ

The symptoms of dying

THE NEW YORK TIMES | Online – 20 June 2017 – Dying has its own biology and symptoms. It's a diagnosis in itself. While the weeks and days leading up to death can vary from person to person, the hours before death are similar across the vast majority of human afflictions. Some symptoms, like the death rattle, air hunger and terminal agitation, appear agonizing, but aren't usually uncomfortable for the dying person. They are well-treated with medications. With hospice availability increasing worldwide, it is rare to die in pain. https://goo.gl/3gGgth

How unscrupulous hospice operators are stealing millions from Medicare

THE FISCAL TIMES | Online – 19 June 2017 – In the latest in a flurry of high-profile Medicare and Medicaid fraud cases, one of the nation's largest skilled nursing, senior living and rehabilitation providers has agreed to pay the federal government $53.6 million to settle a half dozen lawsuits charging that some of its facilities submitted false Medicare claims for unnecessary or never delivered services and provided grossly substandard nursing care. The Pennsylvania-based mega company, Genesis Healthcare, and many of its subsidiaries were held responsible for a panoply of dirty tricks to bilk the government's health care programs for seniors and the poor. Those included billing Medicare for hospice services for patients who were not terminally ill and therefore ineligible for end-of-life care, the Department of Justice announced. Hospice care is available under Medicare to the most vulnerable of patients – usually desperately ill people with only six months to live. The government spent $15.1 billion alone in 2013 to provide the service to roughly 1.3 million patients. https://goo.gl/JnrFSh

Specialist Publications

'Awareness and misperceptions of hospice and palliative care: A population-based survey study' (p.6), in *American Journal of Hospice & Palliative Medicine.*

'Advance care planning in Medicare: An early look at the impact of new reimbursement on billing and clinical practice' (p.9), in *BMJ Supportive & Palliative Care.*

Cont.

Noted in Media Watch 3 April 2017, #506 (p.4):

- *LEXOLOGY* | Online – 27 March 2017 – **'A new frontier in health care fraud: Hospice care.'** The vital and necessary end-of-life services provided by hospice programs are now yielding an increasing number of fraud, waste, and abuse cases. In 2015, the federal government prosecuted over 60 cases of fraud related to hospice providers with a cost to the Medicare program of hundreds of millions of dollars. https://goo.gl/UMOzqw

N.B. Additional articles on Medicare fraud in the U.S. in the context of hospice care are noted in the 19 September 2016 issue of Media Watch (#480, pp.1-2), including *The Washington Post* 2014, seven-part series, 'The business of dying.'

International

Prisons taking role of care homes and hospices as older population soars

U.K. (England & Wales) | *The Guardian* – 20 June 2017 – Prisons are now the largest providers of residential care for frail and elderly men in England & Wales and are increasingly turning into hospices, providing end-of-life care for older prisoners and even managing their deaths. The first report on older prisoners by the prisons and probation ombudsman[1] ... reveals that the number of prisoners over 60 has tripled in 15 years. There will be 14,000 prisoners aged over 50 by 2020, amounting to 17% of the total prison population, up from 13% in 2014. The situation is so serious ... the time has come to introduce purpose-built "old prisoner" jails; essentially, residential care homes surrounded by a wall. The prisons and probation ombudsman's report holds the government to account for abandoning prisons to cope alone with the seismic change in their population. Prison officers are inadequately training in the care of the elderly and often infirm inmates... https://goo.gl/8x4V93

U.S.A.

'Solutions remain elusive as elderly prisoners grow in number' (p.3), in *The Missourian.*

1. 'Thematic Review: Older Prisoners,' Prisons & Probation Ombudsman, 2017. https://goo.gl/hshbkH

End-of-life care in Ireland

End-of-life care: When CPR is wrong

IRELAND | *The Irish Times* (Dublin) – 18 June 2017 – The modern intensive care unit offers a wide range of life support mechanisms so that even the sickest person with multi-organ failure can be kept alive. Parallel to this, the media, and television in particular, has removed any veil of secrecy that may have existed about emergency and intensive care medicine. But it may also have raised expectations to an unreasonable level, with evidence to show that the public perception of the role of cardiopulmonary resuscitation (CPR) is not a realistic one. The inappropriate use of CPR in certain end-of-life situations has been highlighted recently in medical literature. CPR is the appropriate response when someone has a cardiac arrest. However it has no role in the patient who slips away naturally at the end of a long illness. Senior clinicians have expressed concern that doctors who are called at the time of death feel they have no authority to withhold CPR, or they fear the legal risks of doing so – even where CPR is clearly pointless. As a result, patients with terminal cancer or end stage dementia are being vigorously resuscitated rather than allowed to die naturally. https://goo.gl/hDvsZn

Specialist Publications

'Do not resuscitate with no surrogate and no advance directive: An ethics case study' (p.9), in *Journal of Clinical Ethics.*

Cont.

Noted in Media Watch 29 May 2017, #514 (p.7):

- *IRISH JOURNAL OF MEDICAL SCIENCE* | Online – 16 May 2017 – **'Doctors' attitudes towards the introduction and clinical operation of do not resuscitate orders (DNRs) in Ireland.'** A substantial proportion of hospital doctors surveyed demonstrated an incomplete understanding of DNRs and their clinical operation. However, the overwhelming majority believed that domestic guidelines are needed on the matter. https://goo.gl/E9XEti

N.B. Additional articles on national and international resuscitation policies and practices are noted in the 19 June 2017 issue of Media Watch (#517, pp.5-6).

Elder care in the U.K.

Care crisis: This is why Britain's care homes are charging the dead

U.K. | *The Daily Telegraph* – 18 June 2017 – Britain's care sector is plunging deeper into crisis as more evidence emerges of homes applying spiralling, opaque fees to those residents who pay for their own care. Several care homes are now under investigation by the Competition & Markets Authority over allegations that they may have broken the law. The watchdog raised concerns about fees levied after residents have died and questionable upfront fees, both of which may breach the Consumer Rights Act, it said. The investigation was sparked as part of a review of the care sector, with these damning interim findings emerging last week. It also found that people struggled to find and compare care homes and faced difficulties in complaining about poor service. https://goo.gl/MtB1hC

Specialist Publications

'The costs, resource use, and cost-effectiveness of Clinical Nurse Specialist led interventions for patients with palliative care needs: A systematic review of international evidence' (p.7), in *Palliative Medicine.*

N.B. Additional articles on palliative and end-of-life care in care homes and nursing homes are noted in the 12 June 2017 issue of Media Watch (#516, p.9).

End-of-life care in England

East Staffordshire relying too heavily on volunteers to provide end-of-life care, watchdog claims

U.K. (England) | *The Burton Mail* (Burton upon Trent) – 18 June 2017 – A watchdog has found there is an "over-reliance" on volunteers to deliver care and support for people who are dying and their families in East Staffordshire – with "very little" funding allocated to permanent staff.[1] Research led by Healthwatch Staffordshire has revealed "gaps and inconsistencies" in the way end-of-life care is delivered. The body's investigation discovered weaknesses in "advance care planning" – the process during which someone who is dying outlines how they want to be treated. Healthwatch led an end-of-life advisory group alongside representatives from the University Hospital of North Midlands and hospices around the county. Bereavement support offered before and after patients' death was also singled out as an area for improvement. It set out to "explore barriers to a consistent, holistic approach across Staffordshire" and gathered information through focus groups and interviews with care staff and patients. https://goo.gl/J9uc5C

1. 'Think Different, Think End-of-Life Care,' Healthwatch Staffordshire, May 2017. https://goo.gl/XwXJTh

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

The Council's recently published 'Best Practice in Care Coordination for Palliative and End-of-life Care Services: Information for commissioners' is a resource to support commissioners in designing and contracting optimal care coordination systems. This resource is aligned to 'Ambitions for Palliative & End-of-life Care: A national framework for local action 2015-2020,' to be taken in the context of National Health Service England's Commissioning Toolkit for End-of-Life Care. https://goo.gl/1KW2hZ

Specialist Publications

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

Awareness and misperceptions of hospice and palliative care: A population-based survey study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 20 June 2017 – Despite the documented benefits of palliative and hospice care on improving patients' quality of life, these services remain underutilized. Multiple factors limit the utilization of these services, including patients' and caregivers' lack of knowledge and misperceptions. Of the 800 participants [in this cross-sectional study], 664 (83%) and 216 (27%) provided a definition of hospice care and palliative care (PC), respectively. Of those who defined hospice care, 399 (60%) associated it with end-of-life care, 89 (13.4%) mentioned it was comfort care, and 35 (5.3%) reported hospice care provides care to patients and families. Of those who defined PC, 57 (26.4%) mentioned it provided symptom management to patients, 47 (21.9%) stated it was comfort care, and 19 (8.8%) reported it was applicable in any course of an illness. Of those who defined hospice or PC, 248 (37.3%) had a misperception about hospice care and 115 (53.2%) had a misperception about PC. Most community-dwelling adults did not mention the major components of palliative and hospice care in their definitions, implying a low level of awareness of these services, and misinformation is common among community-dwelling adults. https://goo.gl/FBn4ut

Noted in Media Watch 4 April 2016, #456 (p.4):

- U.S. (Louisiana) | *The Louisiana Weekly* (New Orleans) – 29 March 2016 – **'Confusion on palliative care vs. hospice limits help at end-of-life.'** Multiple studies show that, compared to awareness of hospice, "There's significantly less familiarity with palliative care (PC)," said Lyle Fettig, MD, director of Indiana University School of Medicine's Hospice & Palliative Medicine Fellowship program centered in Indianapolis. PC is now a recognized medical subspecialty, but experts in the field say lack of knowledge about it within the general public, and even among medical providers, is impeding the many benefits of these services for those who most need them. http://goo.gl/6gWPHJ

N.B. Additional articles on public awareness and perception of hospice and palliative care are noted in the 25 April 2016 issue of Media Watch (#459, p.2).

The effect of weekly specialist palliative care teleconsultations in patients with advanced cancer: A randomized clinical trial

BMC MEDICINE | Online – 19 June 2017 – Telemedicine is emerging in all fields of medicine, including palliative care (PC). Despite promising earlier research, the present study shows that telemedicine does not necessarily lead to a better quality of advanced cancer care. Indeed, the use of telemedicine might create a situation in which patients experience a higher symptom burden, despite high degrees of satisfaction. Future research and care models should therefore explore the beneficial as well as the potentially harmful aspects of teleconsultations within advanced cancer care, thereby focusing on 1) Ways to optimize multidisciplinary care via teleconsultations,; 2) The appropriate timing and frequency of PC teleconsultations for patients with advanced cancer and other groups of vulnerable patients; 3) Possibilities for patient-tailored, demand-driven teleconsultations; and, 4) The potential impact of technology as such on the patient's sense of wellbeing. https://goo.gl/AFPhXp

N.B. Additional articles on telehealth/telemedicine in the context of end-of-life care are noted in the 13 March 2017 issue of Media Watch (#503, p.12).

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.

End-of-life care in Australia

Health care use and costs at the end of life: A comparison of elderly Australian decedents with and without a cancer history

BMC PALLIATIVE CARE | Online – 21 June 2017 – Results [of this study] suggest wide variation in end-of-life care (EoLC), particularly when comparing decedents with and without a cancer history. Decedents with a cancer history had higher rates health services use and higher associated costs than non-cancer decedents. Age at death was also a determinant of EoLC, with older decedents in both cohorts using fewer health care services than younger decedents. This is the first study of its kind in Australia, yet the results align with studies conducted internationally in terms of the impact of age on health services use and distribution of health care costs, with hospitals being the main driver of end-of-life costs. https://goo.gl/ipH5SW

The costs, resource use, and cost-effectiveness of clinical nurse specialist led interventions for patients with palliative care needs: A systematic review of international evidence

PALLIATIVE MEDICINE | In Press – Accessed 20 June 2017 – The studies reviewed included a wide variety of interventions including clinical, support and education, as well as care coordination activities. The quality of the studies varied greatly. Clinical nurse specialists interventions may be effective in reducing specific resource use such as hospitalizations /re-hospitalizations/admissions, length of stay, and health care costs. There is mixed evidence regarding their cost-effectiveness. https://goo.gl/AQWeHj

Noted in Media Watch 29 May 2017, #514 (p.6):

- AUSTRALIA | Special Broadcasting Service – 24 May 2017 – **'Palliative care need rising in Australia.'** A higher proportion of the Australian population is going to hospital for end-of-life care than ever before. New data shows that palliative care hospitalisations are growing faster than all other hospitalisations – increasing to 19% between 2010-2011 to 2014-2015.[1] https://goo.gl/GNPJfg

  1. 'Palliative care services in Australia,' Australian Institute of Health & Welfare, Canberra, Australian Capital Territory, May 2017. https://goo.gl/nstjol

Related

- *JAMA ONCOLOGY* | Online – 22 June 2017 – **'Hospital-based end-of-life care and costs for older patients with malignant brain tumors.'** Approximately half of patients with a diagnosis of primary malignant brain tumor (PMBT) or secondary malignant brain tumor (SMBT) are older than 65 years and experience disproportionate mortality and symptom burden. End-of-life care (EoLC) for patients with terminal cancer is often aggressive, costly, and discordant with patient preferences. However, a lack of knowledge remains about patterns of EoLC for the growing population of elderly people with a malignant brain tumor. This study compares hospital-based care and costs in the last 30 days of life for older patients with PMBT and SMBT, identifies potential risk factors for aggressive care, and evaluates the association between aggressive care and cost. https://goo.gl/n6PXie

Pilot study of interprofessional palliative care education of medical students in the U.K. and U.S.

BMJ SUPPORTIVE CARE & PALLIATIVE CARE | Online – 21 June 2017 – Educating medical students to care for patients at the end-of-life is increasingly recognised as an essential component of training. Traditionally, medical student programmes are run by doctors, but patient care is delivered by an interprofessional team. The programmes in the U.K. and U.S. [reported on here] independently developed a teaching experience led by an interprofessional team of palliative care (PC) health professionals. This is the first study to ascertain views of an interprofessional team delivering PC education to medical students. Focus groups enable interaction between members of the group as well as the generation of consensus of comments among group members. Despite different structures and settings, this experiential learning in PC provided a rewarding interprofessional experience that has historically been difficult to achieve. https://goo.gl/iS6RWP

Relatives' level of satisfaction with advanced cancer care in Greenland: A mixed methods study

INTERNATIONAL JOURNAL OF CIRCUMPOLAR HEALTH, 2017;76(1). Palliative cancer care in Greenland is provided by health professionals at the national Queen Ingrid's Hospital and at Rigshospitalet in Denmark. The authors examined relatives' level of satisfaction with care and treatment, and their current main concerns. The highest rate of satisfaction was with the availability of a hospital bed (66%), and relatives were the most dissatisfied with the lack of inclusion in decision making related to treatment and care (71%) and the length of time required to diagnose cancer (70%). Responses to open-ended questions revealed that relatives faced challenges in gaining access to information from health professionals. They experienced a lack of security, worries about the future and a lack of support at home. The authors recommend a focus on psychosocial care, more access to information, and to include relatives in decision making and in the future planning of palliative care services. https://goo.gl/aTtKJ6

Related

- *EUROPEAN JOURNAL OF ONCOLOGY NURSING*, 2017;28(4):92-97. '**Symptoms and health-related quality of life in patients with advanced cancer: A population-based study in Greenland.**' Patients with undergoing palliative treatment in Greenland for advanced cancer reported high levels of social and financial problems and reduced physical functioning. This indicates a potential for improving palliative care service and increasing the focus on symptom management. https://goo.gl/7vVjmh

Futile treatment: A review

JOURNAL OF BIOETHICAL INQUIRY | Online – 20 June 2017 – The main goal of intensive care medicine is helping patients survive acute threats to their lives, while preserving and restoring life quality. Because of medical advancements, it is now possible to sustain life to an extent that would previously have been difficult to imagine. However, the goals of medicine are not to preserve organ function or physiological activity, but to treat and improve the health of a person as a whole. When dealing with medical futilities, physicians and other members of the care team should be aware of some ethical principles. Knowing these principles could make decision-making easier, especially in cases where legal guidelines are insufficient or lacking. Understanding of these principles can relieve the pressure that healthcare professionals feel when they have to deal with medical futility. Efforts should be made to promote an ethics of care, which means caring for patients even after further invasive treatment has been deemed to be futile. Treatments that improve patients' comfort and minimize suffering of both patients and their families are equally as important as those aimed at saving patients' lives. https://goo.gl/PaCcyc

Noted in Media Watch 2 January 2017, #493 (pp.13-14):

- *JOURNAL OF CLINICAL ETHICS* | Online – 30 December 2016 – '**Medical futility: A contemporary review.**' The global medical community has seen the development of two distinctly different approaches to medical futility: one in which the autonomy of patients is of paramount importance in the decision whether or not to pursue a treatment; and, one in which beneficence and *primum non nocere* – first do no harm – are almost entirely the clinician's prerogative, and whereby he/she has a duty to refuse any treatment for which the potential risks outweigh the potential benefits for the patient. https://goo.gl/2Rq13L

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 22 June 2017 – '**Understanding factors contributing to inappropriate critical care: A mixed-methods analysis of medical record documentation.**' Factors leading to inappropriate critical care, treatment that should not be provided because it does not offer the patient meaningful benefit, have not been rigorously characterized. Medical record documentation suggests that inappropriate treatment occurs in the setting of communication and decision-making patterns that may be amenable to intervention. https://goo.gl/ya9wcm

Do not resuscitate with no surrogate and no advance directive: An ethics case study

JOURNAL OF CLINICAL ETHICS, 2017;28(2):159-162. Do not resuscitate (DNR) orders are typically signed by physicians in conjunction with patients or their surrogate decision makers in order to instruct healthcare providers not to perform cardiopulmonary resuscitation (CPR). Both the medical literature and CPR guidelines fail to address when it is appropriate for physicians to sign DNR orders without any knowledge of a patient's wishes. The authors explore the ethical issues surrounding instituting a two-physician DNR for a dying patient with multiple co-morbidities and no medical record on file, no advance directives, and no surrogate decision maker. Through this case they also highlight the issues of poor prognostication and the reversal of a DNR in such circumstances. https://goo.gl/chrHrZ

> **N.B.** Additional articles on national and international resuscitation policies and practices are noted in the 19 June 2017 issue of Media Watch (#517, pp.5-6).

The role of relational knowing in advance care planning

JOURNAL OF CLINICAL ETHICS, 2017;28(2):122-134. Medical decision making when a patient cannot participate is complicated by the question of whose voice should be heard. The most common answer to this question is that "autonomy" is paramount, and therefore it is the voice of the unwell person that should be given priority. Advance care planning (ACP) processes and practices seek to capture this sentiment and to allow treatment preferences to be documented and decision makers to be nominated. Despite good intentions, ACP is often deficient because it is unable to facilitate a relational approach to decision making in cases when the patient's competence is reduced. The authors present findings from a study of the ways in which older people and their significant others understand decision making in such circumstances. Critical to the participants' understanding was the emergent concept of "relational knowing," a concept that is poorly articulated in the ACP literature. The authors' findings suggest that the dominant understanding of decision making in conditions of impaired competence is incomplete and obscures much of what matters to people. They conclude that, having recognized a broader set of ethical concerns, it is necessary to develop a relational and narrative based approach that applies in appropriate settings. https://goo.gl/NmefAA

Advance care planning in Medicare: An early look at the impact of new reimbursement on billing and clinical practice

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 21 June 2017 – This single-centre study addressed whether clinicians who have ACP conversations with patients will use the new reimbursement code and if the new reimbursement is successful at motivating clinicians to have more ACP conversations with patients. The authors found that while clinicians are open to using the reimbursement codes, organisational barriers such as low visibility and documentation make it difficult for clinicians to bill for ACP. Moreover, structural and professional factors have rendered Medicare's ACP reimbursement largely ineffective at motivating healthcare providers to perform more ACP conversations during the first 3 months of this policy. https://goo.gl/4jCH9j

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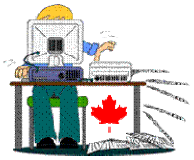

Barry R. Ashpole

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

Related

- *JOURNAL OF PATIENT SAFETY* | Online – 16 June 2017 – **'Can a patient testimonial safely help ensure pre-hospital appropriate critical versus end-of-life care?'** Approximately half of the emergency medical technician (EMT) survey respondents were EMT basic and half were paramedic. Less than half had previous Physician Orders for Life-Sustaining Treatment (POLST) or living will (LW) training. Document clarity ... was rarely evidenced. Video message/testimonial seems to be a helpful aid to both POLST and LWs. https://goo.gl/kuJKcL

Noted in Media Watch 12 December 2016, #491 (p.11):

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION* | Online – 30 November 2016 – **'Understanding what people intend: Is it possible from written advance directives?'** The study by Clemency and colleagues underlines important challenges to understanding and honoring Physician Orders for Life-Sustaining Treatment (POLST) documents in the emergency setting.[1] The issues they raise highlight the limitations of written advance directives in general and POLST documents in particular. https://goo.gl/UqBpfg

    1. 'Decisions by default: Incomplete and contradictory MOLST in emergency care,' *Journal of the American Medical Directors Association*, published online 27 September 2016. [Noted in Media Watch 3 October 2016, #482 (p.14). https://goo.gl/2Ew9LH

A peaceful place in the city: A qualitative study of restorative components of the cemetery

LANDSCAPE & URBAN PLANNING, 2017;167(11):108-117. Cemeteries in Scandinavia are culturally and historically valuable places. In addition, they represent well-maintained green spaces in the urban fabric. The combination of nature, culture, and history makes cemeteries interesting to explore as restorative environments. To the authors' knowledge, no published studies have yet focused on users' perception of the cemetery as a restorative environment. This study therefore set out to initiate research on the topic. A qualitative explorative approach was applied in which we interviewed 59 visitors to a cemetery in Oslo about their use and experiences of the cemetery. The findings support the notion that the combination of nature, culture, and history, as well as respect for the deceased and others visiting graves, contributes to the description of the cemetery as a restorative environment, and makes the cemetery different from other green spaces in the city in that these qualities can foster relaxation, reflection, and contemplation. https://goo.gl/4XULMF

Paediatric palliative care in France

How can the supervision of a paediatric palliative care team allow thinking about life?

MÉDECINE PALLIATIVE | Online – 21 June 2017 – How to ensure the psychological support of the regional resources teams of pediatric palliative care (PC)? While many PC professionals deplore the difficulty to sustain psychological supportive organization within their team, it appeared interesting to describe the supervision of the Midi-Pyrénées paediatric PC team (Toulouse, France), in place since 2013 and which continues to win the approval of all. Lead by an external pedopsychiatrist, this supervision takes place at the hospital during work time. Practical and organizational arrangements are analyzed as well as the movements of anger, depression and aggression that sometimes can be deployed. The containing function of the frame as well as of the supervisor, trained in group facilitation, is described. The attempt to think the unthinkable, the will to get over past sideration triggered by the violent nature of the situations encountered and the search for meaning are portrayed. The caregivers and the group leader will then bear witness of their current experience and how it has evolved over time. Finally, an analysis of the effects of this psychological support organization on the team is developed along with the tools used and the limits of this supervision. The importance of this time for thinking, its impact on team cohesion, and the level of maturity of the team it reveals, are finally be highlighted. https://goo.gl/pXaPLR

N.B. French language article.

Cont.

Related

- *PALLIATIVE MEDICINE* | Online – 19 June 2017 – **'The "surprise" question in paediatric palliative care: A prospective cohort study.'** [This study demonstrated that] the surprise question is a highly sensitive prognostic tool for identifying children receiving palliative care who are in the last 3 and 12 months of life. The tool is accurate at recognising children during stable periods demonstrated through a high negative predictive value. In practice, this tool could help identify children who would benefit from specialist end-of-life care, act as a marker to facilitate communications on advance care planning and assist in resource allocation. https://goo.gl/es3vEA

  N.B. Additional articles on the "surprise question" for predicting death in seriously ill patients are noted in the 10 April 2017 issue of Media Watch (#507, pp.10-11).

- *PEDIATRIC EMERGENCY CARE* | Online – 12 June 2017 – **'An ethical justification for termination of resuscitation protocols for pediatric patients.'** The aim of this article was to compare specific characteristics and outcomes among adult and pediatric out-of-hospital cardiac arrest (OHCA) patients to show that the existing literature warrants the design and implementation of pediatric studies that would specifically evaluate termination of resuscitation protocols. The authors also address the emotional and practical concerns associated with ceasing resuscitation efforts on scene when treating pediatric patients. https://goo.gl/EVA7sU

  N.B. See also 'No small matter: Pediatric resuscitation,' *Current Opinion in Critical Care*, 2017;23(3):193-198, in which the authors present advancements in pediatric cardiac arrest research, highlighting articles most relevant to clinical practice published since the latest international guidelines for cardiopulmonary resuscitation. https://goo.gl/AgdSjB

The "good death" and reduced capacity: A literature review

MORTALITY | Online – 18 June 2017 – Research effort into what a "good death" entails has generally concentrated on six themes: 1) Pain and symptom management; 2) Clear decision-making; 3) Preparation for death; 4) Completion; 5) Contributing to others; and, 6) Affirmation of the whole person. This review explores these themes, specifically examining their applicability to those who lack mental capacity to make their own decisions. Some appear more relevant than others, with clear decision-making and affirmation of personhood predicating issues related to reduced capacity. Largely, however, the literature on a "good death" builds on an underlying assumption that the dying patient is cognisant and capable of rationalising their death. Those instances where mental capacity is acknowledged within the model have been met by criticism from numerous authors. Factors such as the subjectivity of substitute decision-makers and the complexity associated with medico-legal interpretations of current legislation help to highlight deficiencies in the application of principles of a "good death" in practice. Further specific consideration is required on how to achieve a "good death" for those with reduced capacity. https://goo.gl/m7wFfq

Related

- *THE HASTINGS REPORT*, 2017;47(1):28-29. **'A good death.'** This issue of *The Hastings Center Report* offers two articles from authors who strive to provide good end-of-life care and to prevent needless suffering.[1,2] The authors of this editorial agree with their goals, but they express substantial reservations about the approaches recommended. Respect for the decisions of patients and their surrogates is a relatively new and still vulnerable aspect of medical care. For thousands of years, patients and surrogates had no say in medical decision-making. Today, standards support shared decision-making, but these articles both carve out exceptions to those standards, limiting the rights of patients and families in decisions about specific end-of-life treatments. https://goo.gl/u75r67

  1. 'The limits of surrogates' moral authority and physician professionalism: Can the paradigm of palliative sedation be instructive?' *The Hastings Report*, 2017;47(1):20-23. [Noted in Media Watch 16 January 2017, #495 (p.6)] https://goo.gl/OwJ4Ci
  2. 'After the DNR: Surrogates who persist in requesting cardiopulmonary resuscitation,' *The Hastings Report*, 2017;47(1):10-19. [Noted in Media Watch 16 January 2017, #495 (p.6)] https://goo.gl/4CyvmX

Royal College of Nursing to draw up first ever protocol for "animal therapy"

NURSING TIMES | Online – 22 June 2017 – The College has announced that it will create the first ever nationwide protocol for animals in healthcare in a bid to encourage more hospitals to explore the therapy area. https://goo.gl/UER6XK

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

Nursing support of home hospice caregivers on the day of patient death

ONCOLOGY NURSING FORUM, 2017;44(4):457-464. Nurses [i.e., study participants in nine hospices in Utah, Oregon, and Massachusetts] reported that their communication skills were less effective when discussing difficult topics as compared to their overall communication effectiveness. Eleven patients died before the nursing visit, 3 died during the visit, and 30 died post-visit. Nurses primarily engaged in discussions facilitating caregiver emotional, tangible, and informational support. More informational support was observed when patient death occurred during the nursing visit. Time spent in general conversation showed that physical care conversations predominated (80% of the average overall amount of conversation time), compared to lifestyle/psychosocial discussions (14%) and spiritual discussions (6%). Spiritual discussions were observed in only 7 of 44 hospice visits. Spiritual discussions, although short and infrequent, were significantly longer, on average, for caregivers without a religious affiliation. Communication skills programs can potentially increase self-reported communication effectiveness. Emerging acute spiritual concerns, particularly for caregivers without a previous religious affiliation, should be anticipated. https://goo.gl/Z7TxL3

Related

- *MORTALITY* | Online – 20 June 2017 – **'Difficulties for a practitioner preparing a family for the death of a parent: A narrative inquiry.'** The practitioners [i.e., study participants] failed to facilitate advanced family preparation despite several attempts. Even with a clear understanding of processes and willingness to facilitate difficult conversations, practitioners face tensions between respect for a dying patient's needs, avoiding undermining the family culture and meeting children's needs. Contrary to the requirement to practise from an evidence base, some situations require the ability to work with "not knowing." https://goo.gl/QeRjVd

The meaning and experience of bereavement support: A qualitative interview study of bereaved family caregivers

PALLIATIVE & SUPPORTIVE CARE | Online – 21 June 2017 – While considered standard within palliative care (PC) services in Australia, bereavement support is not widely utilized by family caregivers. There is little research focused on the forms of bereavement support desired or required by family caregivers, how such care is viewed, and/or how bereavement support is experienced. This paper reports on one aspect of a broader study designed to explore a range of experiences of patients and caregivers to and through PC. The research identified four prevalent themes: 1) Socio-cultural constructions of bereavement support as for the incapable or socially isolated; 2) Perceptions of bereavement support services as narrow in scope; 3) The "personal" character of bereavement and subsequent incompatibility with formalized support; and, 4) Issues around the timing and style of approaches to being offered support. https://goo.gl/5qYu6f

Related

- *MORTALITY* | Online – 23 June 2017 – **'An Italian American view of grief: connection, transformation and resilience.'** Current theories regarding grief and mourning often acknowledge continued connection and reworking of the relationship to the lost person rather than relinquishing ties and bonds, and acknowledge the importance of culture in grief and mourning. Although there is little research regarding Italian Americans and grieving, these ideas fit well with the description described by researchers as "Italians tend to keep their dead with them." This paper explores Italian American responses to the loss of a loved one. https://goo.gl/LgLonx

Supporting Muslim patients during advanced illness

THE PERMANENTE JOURNAL, 2017;21(2):16-190. Religion is an important part of many patients' cultural perspectives and value systems that influence them during advanced illness and toward the end of life when they directly face mortality. Worldwide violence perpetrated by people identifying as Muslim has been a growing fear for people living in the U.S. and elsewhere. This fear has further increased by the tense rhetoric heard from the recent U.S. presidential campaign and the new presidential administration. For many, this includes fear of all Muslims, the second-largest religious group in the world with 1.6 billion adherents, and approximately 3.5 million in the U.S. alone. Patient-centered care requires health professionals to look past news headlines and unchecked social media so they can deliver high-quality care to all patients. This article explores areas of importance in the context of advanced illness for practitioners of Islam. These include the conditions needed for prayer, the roles of medical treatment and religious authority, the importance of modesty, the religious concordance of clinicians, the role of family in medical decision making, advance care planning, and pain and symptom management. Initial recommendations to optimize care for Muslim patients and their families, informed by the described tenets of Muslim faith, are provided for clinicians and health systems administrators. https://goo.gl/CHC3UF

Extract from *The Permanente Journal* article

Interprofessional training focused on care in advanced illness for older Muslim patients might include a review of the following: The Five Pillars of Islam, procedures related to prayer, principles of pain/symptom management, role of family and religious leaders in health decisions, Islamic definition of death, obligation to preserve life and the exceptions, and procedures related to death. With the growing focus on interprofessional health professions education and interdisciplinary health care delivery, it may be beneficial to add a Muslim clinician to the health care team in areas where there are substantial Muslim populations. Similarly, Muslim chaplains should be made available in health care facilities, working collaboratively with local imams and facility staff to respond to patients' needs.

Noted in Media Watch 10 April 2017, #507 (p.10):

- *AVICENNA JOURNAL OF MEDICINE*, 2017;7(2):35-45. **'Do not resuscitate, brain death, and organ transplantation: Islamic perspective.'** Muslim patients and families are often reluctant to discuss and accept fatal diagnoses and prognoses. In many instances, aggressive therapy is requested by a patient's family, prolonging the life of the patient at all costs. Islamic law permits the withdrawal of futile treatment, including life support, from terminally ill patients allowing death to take its natural course. "Do not resuscitate" is permitted in Islamic law in certain situations. https://goo.gl/NW9OkG

N.B. Additional articles on the Islamic perspective on death, end-of-life, and end-of-life care are noted in the 14 November 2016 issue of Media Watch (#487, p.11).

Considering diversity in nursing and palliative care – the example of migrants

ZEITSCHRIFT FÜR GERONTOLOGIE UND GERIATRIE | Online – 14 June 2017 – Our society is characterized by increasing diversity. Immigrants greatly contribute to this diversification. Currently, one fifth of the population in Germany is considered to be of immigrant origin. Healthcare needs of immigrants are often not sufficiently taken into account by healthcare institutions. This may result in many barriers encountered by immigrants in the healthcare system, which may affect the utilization and quality of care. These barriers are particularly pronounced in nursing and palliative care. Current strategies aiming to reduce these barriers are limited as they often only focus on culture and religion, thereby neglecting the role of other diversity dimensions, such as sex and socioeconomic status. Diversity management is able to overcome these shortcomings by implementing conditions in healthcare institutions which promote awareness and openness towards the diversity of healthcare clients. This can improve the quality of care and can contribute to patient-oriented healthcare. https://goo.gl/odVvvu

N.B. German language article.

Cont.

Noted in Media Watch 12 June 2017, #516 (p.13):

- *PLOS ONE* | Online – Accessed 5 June 2017 – **'"If I had stayed back home, I would not be alive any more…": Exploring end-of-life preferences in patients with migration background.'** The 37 interviewees (19 native Germans and 18 patients from Europe and the U.S., Israel, Turkey and Indonesia) expressed eleven themes covering health care- and patient-related issues, of which four emerged to be specific for migrants: 1) Worse survival in home country; 2) The perception of an altered identity and "not belonging"; 3) Language skills as prerequisite to survive; and, 4) Longing for "home" while being attached to Germany. From these categories, three overarching themes were derived: 1) A limited understanding of the concept of palliative care; 2) The suppression of end-of-life discussions for its association with suffering and loss of autonomy; and, 3) The significance of complex individual migration histories. https://goo.gl/D2ZHiB

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMC PSYCHIATRY* | Online – 23 June 2017 – **'Euthanasia for people with psychiatric disorders or dementia in Belgium: Analysis of officially reported cases.'** While euthanasia on the grounds of unbearable suffering caused by a psychiatric disorder or dementia remains a relatively limited practice in Belgium, its prevalence has risen since 2008. If, as this study suggests, people with psychiatric conditions or dementia are increasingly seeking access to euthanasia, the development of practice guidelines is all the more desirable if physicians are to respond adequately to these highly delicate requests. https://goo.gl/37fVJF

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 20 June 2017 – **'Belief in life after death and attitudes toward voluntary euthanasia.'** Research has documented associations among religious affiliation, religious practice, and attitudes toward voluntary euthanasia, yet very few studies have investigated how particular religious beliefs influence these attitudes. The author used data from the General Social Survey to evaluate the association between the belief in life after death and attitudes toward voluntary euthanasia. He found that those who believe in life after death are significantly less likely than those who do not believe in life after death or those who doubt the existence of life after death to have positive attitudes toward voluntary euthanasia. https://goo.gl/NLSBMz

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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Cont.

Something Missed or Overlooked?

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

Worth Repeating

Compassion: A scoping review of the healthcare literature

BMC PALLIATIVE CARE | Online – 19 January 2016 – The importance of compassion within healthcare, while seemingly self-apparent and frequently referenced in the literature, has received little in the way of empirical attention over the past quarter century. Important clinical studies are emerging and are collectively contributing to a body of evidence that brings insight to compassion in clinical care. However, these studies often rely on preconceived theoretical definitions of compassion that lack specificity, clinical applicability, conceptual validity, and fail to adequately incorporate the understandings and experiences of patients. As a result, compassion is arguably one of the most referenced principles of quality care for which there is little empirical evidence. Compassion is inextricably linked to the inherent qualities of clinicians being actualized through acknowledgment, engagement and action in response to patient suffering. Clinicians' capacity for compassion is largely determined by their baseline qualities, qualities that can be either nurtured or eroded within clinical and educational settings. While this review has identified a multiplicity of directions for future research, two directions seem paramount. First, there is a need to reset the empirical foundation of compassion research by establishing its conceptual specificity, thereby providing a scientific base to conduct future research on the topic that is marked by validity and rigor. Second, there is a pressing need for applied research, investigating compassion within the clinical setting, as it is at the bedside that compassion seems to either flourish or falter. Future research on the nature of compassion and its application in clinical practice needs to incorporate the perspective of patients, who desperately desire and increasingly expect compassion to be a core component of their healthcare experience. [Noted in Media Watch 25 January 2016, #446 (p.8)] http://goo.gl/CoL1EU

Quotable Quotes

How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving and tolerant of the weak and strong. Because someday in your life you will have been all of these. **George Washington Carver (1864-1943)**

Noted in Media Watch 9 November 2015, #435 (p.14):

- *JOURNAL OF MEDICAL ETHICS* | Online – 3 November 2015 – '**Smiling through clenched teeth: Why compassion cannot be written into the rules.**' The discourse on the failings of the National Health System [in the U.K.] often cites lack of compassion as an important factor. This has resulted in proposals to enact rules which aimed at enforcing compassion in healthcare workers so as to improve the quality of healthcare and avoid future scandals. This paper argues that compassion cannot be enforced by any rule. http://goo.gl/hAb8Fn

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/UDj2IO

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: https://goo.gl/IXO4mD

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

Canada

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

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/5d1I9K

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

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