Media Watch...

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

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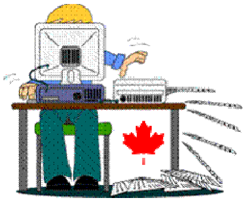

Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'Health care professionals' responses to religious or spiritual statements by surrogate decision makers during goals-of-care discussions' (p.9), in *JAMA Internal Medicine*.

Canada

Multi-institutional audit

Third of dying hospital patients marked to receive CPR against their wishes, Canadian study says

THE NATIONAL POST | Online – 23 November 2015 – More than a third of elderly, gravely ill hospital patients are tagged to receive cardiopulmonary resuscitation (CPR) even though they don't want the painful and usually futile measure, concludes a new Canadian study.[1] The authors call the unwanted orders for CPR on the sickest patients a type of medical error, and say it's the result of a communications breakdown hospitals need to confront. Despite heroic depictions of emergency resuscitation in popular entertainment, attempts to restart an arrested heart rarely save anyone's life. They also take a toll both on patients and the family members who have to watch, says Dr. Daren Heyland, who headed the research. "This is about invasive, aggressive, expensive life-sustaining treatments, used against people's wishes," said the critical care physician and Queen's University [Kingston, Ontario] professor. "Most people's concept of the dying moment is a tender moment, a warm moment, the family around you, holding your hand, preserving dignity. The reality for people undergoing resuscitation is the opposite of that." http://news.nationalpost.com/news/canada/third-of-dying-hospital-patients-marked-to-receive-cpr-against-their-wishes-canadian-study-says

Specialist Publications

'Medical student training on code status discussions: How far have we come?' (p.11), in *Journal of Palliative Medicine.*

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1. 'The prevalence of medical error related to end-of-life communication in Canadian hospitals: Results of a multicentre observational study,' *BMJ Quality & Safety*, 9 November 2015. [Noted in Media Watch, 16 November 2015, #436 (p.10)] http://qualitysafety.bmj.com/content/early/2015/11/08/bmjqs-2015-004567.abstract

Ontario plans to target home care in overhaul of health care system

ONTARIO | *The Globe & Mail* – 23 November 2015 – The Ontario government is preparing to overhaul health care in the province, including scrapping its troubled system for delivering home care and reforming primary care with the aim of improving patient access. The proposed changes, mapped out in a paper to be made public in the coming weeks, will be the focus of consultations in the new year and are expected to touch on all aspects of the health system. A centrepiece of the proposals will be the expansion of the role played by the province's Local Health Integration Networks. At the same time, the province would eliminate Ontario's 14 Community Care Access Centres, the public agencies responsible for overseeing the delivery of services such as nursing, physiotherapy and help with personal care for the sick and the elderly in their homes. The agencies have long been a lightning rod for criticism, and were the focus of a *Globe & Mail* investigation this year that found inconsistent standards of care and a lack of transparency that left patients and their families struggling to access services.[1] A report this fall from Ontario Auditor-General Bonnie Lysyk found that as little as 61 cents out of every dollar spent by the agencies goes to face-to-face client services, and discovered gaps in the level of care offered across the province.[2] A second report on home care will be included in the Auditor-General's annual report in December. http://www.theglobeandmail.com/news/national/ontario-government-to-overhaul-health-care-services/article27447577/

1. See the issue of Media Watch of 20 July 2015, #419 (pp.1-2).

2. 'Community Care Access Centres – Financial Operations & Service Delivery,' Office of the Auditor General of Ontario, September 2015. [Noted in Media Watch, 28 September 2015, #429 (p.2)] http://www.auditor.on.ca/en/reports_en/CCACs_en.pdf

N.B. See also the December 2014 report of the Office of the Auditor General of Ontario, in particular pp.258-288 on end-of-life care in the province. [Noted in Media Watch, 15 December 2014, #388 (p.2)] http://www.auditor.on.ca/en/reports_en/en14/308en14.pdf

Related:

- *THE GLOBE & MAIL* | Online – 25 November 2015 – **'Victorian Order of Nurses shutting operations in six provinces.'** The Victorian Order of Nurses has been struggling financially for years and recently decided that it had to shut down its operations in six provinces and cut the size of its head office. The non-profit health organization provides home nursing care and is closing programs in Alberta, Saskatchewan, Manitoba, New Brunswick, Prince Edward Island, and Newfoundland and Labrador. http://www.theglobeandmail.com/news/national/victorian-order-of-nurses-shutting-operations-in-six-provinces/article27478633/

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online – 26 November 2015 – **'MPs and senators to expedite legislation on right to die.'** Government House leader Dominic LeBlanc, in an interview with CBC Radio's The House, said an "immediate objective" is to create a joint committee with members from the House of Commons and the Senate to prepare legislative recommendations for the government. His colleague, Justice Minister Jody Wilson-Raybould, will speak to details around the time frame and response to the 6 February 2016 deadline for new legislation imposed by the Supreme Court of Canada. His task is to ensure Parliament is engaged in the process in light of that deadline. http://www.cbc.ca/news/politics/doctor-assisted-dying-court-parliament-1.3338607

- QUEBEC | CBC News (Montreal) – 26 November 2015 – **'Doctor-assisted death in Quebec could face delay: Health Minister Gaétan Barrette.'** Quebec's new law allowing doctor-assisted death is set to take effect 10 December. Barrette said a Quebec court heard arguments Wednesday in an injunction request filed by a provincial physicians' group. If the injunction is granted, Quebec will have to abide by that decision. http://www.cbc.ca/news/canada/montreal/medically-assisted-death-suicide-quebec-1.3338470

U.S.A.

Wishes for end-of-life care are common across ethnicities

CALIFORNIA | *Kaiser Health News* – 23 November 2015 – What kind of care do you want at the end of your life? Stanford University researchers put that question to members of three major ethnic groups in the Bay Area [of San Francisco] and, in an analysis, found little variation in their responses.[1] "There is a common humanity — people want to live as long as they have good quality of life. When it is their time, they want to be consulted so they die in a way that they are respected, and they don't want their families burdened," said the study's lead author, Dr. V.J. Periyakoil, director of the Stanford Palliative Care Education & Training Program and associate director of palliative care services at the Veteran Affairs Palo Alto Health Care Center. Regardless of ethnicity, however, the researchers found that access to high-quality end-of-life care is often hampered by lack of financial means, poor communication with health providers, cultural mores and family conflicts. http://khn.org/news/deficiencies-in-end-of-life-care-extend-across-ethnicities/

Specialist Publications

'Latinos with chronic kidney failure treated by dialysis: Understanding their palliative care perspectives' (p.7), in *American Journal of Kidney Disease.*

'Rural-urban differences in costs of end-of-life care for elderly cancer patients in the U.S.' (p.12), in *Journal of Rural Health.*

1. 'Patient-reported barriers to high-quality, end-of-life care: A multiethnic, multilingual, mixed-methods study,' *Journal of Palliative Medicine*, 17 November 2015. [Noted in Media Watch, 23 November 2015, #437 (p.13)] http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0403

International

What treatment should doctors prescribe to end suffering?

AUSTRALIA | *The Age* – 26 November 2015 – Most would agree with Andrew Denton that doctors shouldn't look away when the dying are suffering. That would be negligence of the highest order. But what then should doctors do in the face of suffering? A major voice in the recognition and treatment of suffering for 30 years has been Dr. Eric Cassell, an American Physician. In his seminal paper 'The nature of suffering and the goals of medicine'[1] ... Cassel importantly asserts that the relief of suffering and the cure of disease must be viewed as joint obligations of a profession dedicated to the care of the sick. In its essence, suffering threatens the intactness and integrity of personhood. Though commonly restricted to physical realms and bodily disorders such as pain, for many suffering entrenches the mind, soul and spirit. It overwhelms through the loss of meaning, hope and emotional strength in the face of illness. There can be pain (or other symptoms) with no suffering and yet intense suffering without symptoms. For the aged and chronically ill especially, suffering arises from the threat of a future of isolation, loneliness and dependency. Doctors share the lament of suffering. Modern medical training with its preoccupation with "disease" equips the physician with diagnostic, clinical, surgical and pharmaceutical tools. However, it regretfully fails to proffer the "suffering tool." As a result, some doctors may turn away in the face of suffering out of feeling helpless and powerless to provide the relief patients and families need. http://www.theage.com.au/comment/right-to-life-what-treatment-should-doctors-prescribe-to-end-suffering-20151125-gl7g98.html

1. 'The nature of suffering and the goals of...,' *New England Journal of Medicine*, 1982;306(11):639-645. file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/UPG4XG0C/The-Nature-of-Suffering-and-the-Goals-of-Medicine.pdf

End-of-life care in Australia

Bid for clarity on end-of-life care legislation

AUSTRALIA (Tasmania) | *The Mercury* (Hobart) – 26 November 2015 – A Labour member of parliament (MP) hopes she can find a middle ground in one of the community's most difficult debates with a new Bill covering end-of-life care. Madeleine Ogilvie ... does not support euthanasia, believes there remains a need for a better legislative framework around care for the dying. Her draft 'Dying with Care & Consent to Medical Treatment Bill' is modelled on similar legislation in South Australia and has won the endorsement of her mostly Left-leaning parliamentary Labor Party colleagues. "People need a clearer idea of what their rights and responsibilities are, as some people are better prepared for end-of-life decisions than others," Ms. Ogilvie said. Features of the Bill include: 1) A new position of Public Advocate to be created to resolve disputes around end-of-life care and decision making; 2) Giving dying people the right to palliative care but also to protect them from medical treatment that is "intrusive, burdensome and futile"; 3) Ensuring same-sex partners have the same rights to access Public Advocate assistance as *de facto* and married heterosexual couples when it comes to decisions around their partner's end-of-life care; and, 4) Protection for medical practitioners administering care to a person who is dying, particularly in circumstances where treatments are withdrawn or when treatment to relieve pain or distress may have the incidental effect of hastening the death of the patient. http://www.themercury.com.au/bid-for-clarity-on-end-of-life-care-legislation/story-fnj3twbb-1227623174699

End-of-life care in Scotland

Patients should have "right" to end-of-life care, say Members of the Scottish Parliament

U.K. (Scotland) | BBC News – 25 November 2015 – The Scottish Parliament's Health & Sport Committee has published the findings of its report into palliative care (PC).[1] It said there may be 10,000 people in Scotland not getting care they need. It said those with terminal illnesses other than cancer, the homeless and those with learning disabilities were less likely to receive PC at the end of their lives. The committee stressed that care for those who are approaching the end of their life should be based on need, and not what condition they are diagnosed with. The Members of the Scottish Parliament said there is "a perception that cancer patients receive better PC." While increasing numbers of people with other terminal conditions are on the PC register, the committee's report said "there still remains an issue with access to PC for people with non-malignant diseases." Calling for PC to be a right, committee convener Duncan McNeil said: "Our committee came to a firm conclusion that everyone who needs it should be able to access high quality, person-centred PC. We heard that this is not happening on a consistent basis and that people across Scotland have a different experience depending on where they live, their age, and their condition." http://www.bbc.com/news/uk-scotland-34917447

1. 'We need to talk about palliative care,' Health & Sport Committee, Scottish Parliament, November 2015. http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/94230.aspx

N.B. For articles, reports etc., related to the Committee's review of end-of-life care in Scotland published in recent months see the issues of Media Watch of 23 November 2015, #437 (pp.7-8), 9 November 2015, #435 (p.6), 28 September 2015, #429 (p.8), and 21 September 2015, #428 (p.6).

Home care in Wales

Welsh law holds care home providers accountable for failings

U.K. (Wales) | *Care Home* – 25 November 2015 – A new law will make care providers face tougher regulation and inspection in Wales and hold them to account for failings. The new Regulation & Inspection of Social Care (Wales) Bill, passed by Welsh Assembly Members, will also give Ministers the power to remove not just bad services but also bad providers. The Bill includes a "fit and proper person" test for service providers and responsible individuals. http://www.carehome.co.uk/news/article.cfm/id/1572515/New-Welsh-law-to-register-frontline-care-workers-leaves-England-behind

End-of-life care in Taiwan

Survey finds high support for doctors' immunity from palliative care

TAIWAN | *Focus Taiwan* (Taipei) – 24 November 2015 – A recent survey has found that 95% of respondents support signing a document indicating their wish for palliative care (PC) if they suffer serious incurable illness, while 97% back physicians' legal immunity if they provide PC upon patient request. The survey was conducted by the Taipei-based Consumers' Foundation... It was part of a campaign by the foundation to push for a draft patient self-determination act, which aims to provide improved life quality for terminally ill patients and others who suffer from severe diseases that are incurable, to help them live as comfortably as possible without useless medical intervention. Although physicians are allowed to perform PC at the request of a patient, they face the pressure from the patient's families, who may file lawsuits against the doctor due to differences of opinion on the use of PC, accusing the doctor of not trying hard enough to save the patient, the Foundation said. http://focustaiwan.tw/news/asoc/201511240028.aspx

2015 Quality of Death Index

Taiwan – Leading the way

Taiwan ranks near the top ... coming first in Asia and sixth overall.[1] Its high position is the result of a number of factors. Firstly, the availability of palliative care (PC) services has steadily grown in recent years with hospice programs increasing more than 50% to 77 programs during 2004-2012 and hospital-based PC teams multiplying from 8 to 69.

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World' (see Taiwan case study pp.49-50), Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (pp.1,3,6,15,19)]

English language edition:
http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Chinese language edition:
http://www.economistinsights.com/sites/default/files/2015%20Quality%20of%20Death%20Index%20FINAL%20SC.pdf

Ugandan prison guards learn elements of end-of-life care to take back to their jails

UGANDA | *The Yellow Advertiser* (U.K.) – 24 November 2015 – A group of Ugandan prison guards, in the U.K. to learn elements of end-of-life care they could transfer back to their jails, visited Fair Havens Hospice [in Essex]. The visit was part of a three-month training secondment to the U.K. The group will learn about the British justice system, visit prisons, watch cases at the Old Bailey, and take part in a Human Rights course. The African Prisons Project, which provides assistance with healthcare, education, access to justice, and community reintegration for prisoners in Uganda and Kenya, and other African countries, is a partner in the initiative. http://www.yellowad.co.uk/article.cfm?id=108077&headline=Ugandan%20prison%20guards%20learn%20elements%20of%20end%20of%20life%20care%20to%20take%20back%20to%20their%20jails&sectionIs=news&searchyear=2015

Prison Hospice Backgrounder

End-of-life care – or the lack of – in the prison system has been highlighted on a regular basis in Media Watch. An updated compilation of the articles, reports, etc., noted in past issues of the weekly report is available on the Palliative Care Community Network website at: http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons

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.14.

U.K. Child Bereavement Network

Almost 40,000 children bereaved each year by loss of a parent

U.K. | *Nursery World* – 23 November 2015 – Never before published data suggests that last year an estimated 40,000 children and young people across the U.K. faced the death of a parent. The estimates, published by the Child Bereavement Network – part of the National Children's Bureau – are based on local authority age banded mortality statistics for 2014 from the Office for National Statistics and 2011 census data on the proportion of adults living with dependent children, as well as the average number of children by family size.[1] The aim of the data ... is to help services supporting bereaved children to understand their local community better and prioritise filling gaps in provision so more children and their families get the help they need. http://www.nurseryworld.co.uk/nursery-world/news/1154880/almost-40-000-children-bereaved-each-year-by-loss-of-a-parent

Specialist Publications

'Who wants to live forever? Living, dying and grieving in our digital society' (p.14), in *Social Sciences*.

1. Child Bereavement Network data for each local authority in England, Northern Ireland, Scotland and Wales: http://www.childhoodbereavementnetwork.org.uk/research/local-statistics.aspx

N.B. Resources: 'Support Services for Grieving or Bereaved Children: Needs Assessment – Literature Search,' file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/G9UWWHL9/ChildrenandYouthCollaborativeFinalLiteratureSearch.pdf; Supplement to the literature search on helplines, online support, and social media. file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/UPG4XG0C/SupplementChildYouthGriefCollaborativeROPFINAL_2015_20150514162617.pdf. Both undertaken for the 'Children's Anticipatory Grief & Bereavement Collaborative,' Region of Peel, Ontario, Canada, March 2015.

Elder care in the England

Half of U.K. care homes will close unless £2.9 billion funding gap is plugged, charities warn

U.K. (England) | *The Guardian* – 21 November 2015 – Up to half of Britain's care homes will close and the National Health Service will be overwhelmed by frail, elderly people unless the chancellor, George Osborne, acts to prevent the "devastating financial collapse" facing social care, an alliance of charities, local councils, and carers has warned. In a joint letter, 15 social care and older people's groups urge Osborne to use his [upcoming] spending review ... to plug a funding gap that they say will hit £2.9 billion by 2020. They warn that social care in England, already suffering from cuts imposed under the [former Conservative Party and the Liberal Democrats] coalition, will be close to collapse unless money is found to rebuild support for the 883,000 older and disabled people who depend on personal care services... http://www.theguardian.com/society/2015/nov/21/half-uk-care-homes-close-funding-gap-nhs-george-osborne

Related:

- *THE NETHERLANDS* | *Dutch News* – 27 November 2015 – **'Home care sector in crisis, biggest agency on verge of going bust.'** The Netherlands' biggest home care agency, with 12,000 workers and 40,000 clients, is on the verge of bankruptcy. TSN Thuiszorg applied for court protection from creditors, blaming government spending cuts for its troubles. Earlier this month, the courts ruled TSN could not cut the wages of its workers by between 20% and 30%, which the company said it needed to do to make ends meet. The entire home care sector is in a similar situation, Jongstra said. Home care agencies provide cleaning, light nursing and other tasks for the frail elderly and housebound. http://www.dutchnews.nl/news/archives/2015/11/home-care-sector-in-crisis-biggest-agency-on-verge-of-going-bust/

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

Latinos with chronic kidney failure treated by dialysis: Understanding their palliative care perspectives

AMERICAN JOURNAL OF KIDNEY DISEASES | Online – 20 November 2015 – The cultural values of Latinos have a major impact on their palliative care (PC) preferences and healthcare providers should be sensitive to their perspectives, according to a research letter by physicians at the University of Colorado School of Medicine. Lilia Cervantes, MD, assistant professor of medicine, the lead author of the letter, said she individually surveyed 61 Spanish and English-speaking Latino patients who were receiving dialysis to treat kidney failure between September and December 2014 and compared their responses with a previous study of Canadian patients in similar circumstances.[1] "We observed a preference towards more aggressive care," said Cervantes. The letter ... says that fewer patients in the Canadian cohort stated a preference for resuscitation (38.9%) and many (60.7%) regret starting dialysis. Among the Latinos in Cervantes' study, the majority (70%) would prefer resuscitation if their heart stopped and few (15%) regret the decision to start dialysis. In the study of Canadian patients, most wanted to discuss end-of-life decision-making when they became seriously ill. The Latinos in Cervantes' survey preferred an earlier approach with conversations occurring soon after they've started dialysis and while at home to allow for meaningful integration of family into medical decision-making. "Our findings support the relevance of delivering PC in a way that is sensitive to Latino culture and aligns with their values," Cervantes said. http://www.ajkd.org/article/S0272-6386(15)01310-4/fulltext

1. 'End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease,' *Clinical Journal of the American Society Nephrology*, 2010;5(2):194-204. [Noted In Media Watch, 18 January 2010, #132 (p.5)] http://cjasn.asnjournals.org/content/5/2/195.full

Who am I to decide whether this person is to die today? Physicians' life-or-death decisions for elderly critically ill patients at the emergency department-ICU interface: A qualitative study

ANNALS OF EMERGENCY MEDICINE | Online – 24 November 2015 – These qualitative findings highlight the cognitive heuristics and biases, inter-physician conflicts, and communication gaps influencing physicians' triage and end-of-life decisions for elderly critically ill patients at the emergency department-intensive care unit (ED-ICU) interface and suggest strategies to improve these decisions. Six themes emerged: 1) Physicians revealed a representation of elderly patients that comprised both negative and positive stereotypes, and expressed the concept of physiologic age; 2) These age-related factors influenced physicians' decision making in resuscitate/not resuscitate situations; 3) Three main communication patterns framed the decisions: interdisciplinary decisions, decisions by two physicians on their own, and unilateral decisions by one physician; however, some physicians avoided decisions, facing uncertainty and conflicts; 4) Conflicts and communication gaps occurred at the ED-ICU interface and upstream of the ED-ICU interface; 5) End-of-life decisions were perceived as more complex in the ED, in the absence of family or of information about elderly patients' end-of-life preferences, and when there was conflict with relatives, time pressure, and a lack of training in end-of-life decision making; and, 6) During decision making, patients' safety and quality of care were potentially compromised by delayed or denied intensive care and lack of palliative care. http://www.annemergmed.com/article/S0196-0644(15)01360-8/abstract

Palliative care coding practices in Canada since the introduction of guidelines and the hospital standardised mortality ratio indicator

BMJ OPEN | Online – 23 November 2015 – The introduction of a national coding standard resulted in increased identification of palliative patients and services. Aside from palliative care (PC) coding practices, the authors note numerous independent drivers of improving hospital standardised mortality ratio (HSMR) results, notably, a significant reduction of in-hospital mortality, and increase in admissions accompanied by a greater number of coded co-morbidities. While PC impacts the HSMR indicator, its influence remains modest. http://bmjopen.bmj.com/content/5/11/e008753.full

End-of-life care in Sri Lanka

A good death in Ratnapura : A qualitative study

CEYLON JOURNAL OF OTOLARYNGOLOGY, 2015;4(1):20-25. The main categories of [a] good death were having a good family relationship, having a good relationship with medical staff, not being aware of death, fighting against the disease, dying at ones favourite place, having faith, maintaining hope, maintaining dignity, freedom from pain, physical and psychological symptoms, not being a burden to others, and maintaining [a] sense of control. One main drawback of the study was the patients interviewed were mainly from a very low educational and socio-economic level. Their views on a good death might not be the same as the general public in Ratnapura. file:///C:/Users/admin/Downloads/5225-18635-1-SM.pdf

Agency in the context of social death: Dying alone at home

CONTEMPORARY SOCIAL SCIENCE | Online – 20 November 2015 – Each year, a number of bodies are found of people who have died alone at home and whose absence from daily life has not been noticed. Media reports tend to cast either these individuals as deviant, or wider society as having abandoned them to a lonely death. This paper proposes an alternative view, one in which some individuals choose to withdraw from society and enter a period of social death prior to their biological deaths. They may then be subject to a renewed social life after death, brought about through post-death social processes. http://www.tandfonline.com/doi/abs/10.1080/21582041.2015.1114663

Noted in Media Watch, 13 April 2015, #405 (p.8):

- *EUROPEAN JOURNAL OF CANCER CARE* | Online – 7 April 2015 – **'Older people living alone at home with terminal cancer.'** This study describes the lived experiences of older people coping with terminal cancer and living alone, focusing on how they face challenges of the biographical life changes from their disease progression. http://onlinelibrary.wiley.com/doi/10.1111/ecc.12314/abstract

Noted in Media Watch, 1 April 2013, #299 (p.12):

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 27 March 2013 – **'A longitudinal study of end-of-life preferences of terminally-ill people who live alone.'** As a home death seems to be the perceived ideal, terminally ill people who live alone are at a disadvantage in terms of their place of care and death and little is known about their end-of-life preferences. This study aimed at eliciting patient preferences for their place of care and death longitudinally at two points during their illness trajectory, and reporting on the extent they were able to achieve their place of choice or congruence between preferred and actual place of death. http://onlinelibrary.wiley.com/doi/10.1111/hsc.12039/abstract

Dark hospitality: Hotels as places for the end of life

HOSPITALITY & SOCIETY, 2015;5(2-3):233-248. This article explores through the concept of dark hospitality why some people choose to die in a hotel, rather than at home, in a hospice or a hospital. Through in-depth interviews with hotel managers and junior staff at four luxury city hotels, this issue was explored from the perspective of ordinary hotel guests, all of whom had a long-term relationship with the hotel where they died. The hotel staff suggested the reasons why some people choose to die in a hotel include loneliness, fear and minimizing emotional distress for their friends and relatives. The impact of managing such guests is also investigated and the results suggest although managers do care about the impact on the reputation of the hotel, they, along with their staff, are very much affected emotionally by these types of planned deaths. The suggestion emerged from the interviews that with an increasing ageing population, perhaps in the not-too-distant future, the 'hospice hotel' could emerge as a new commercial hospitality product. http://www.ingentaconnect.com/content/intellect/hosp/2015/00000005/F0020002/art00009

Multicenter U.S. study

Health care professionals' responses to religious or spiritual statements by surrogate decision makers during goals-of-care discussions

JAMA INTERNAL MEDICINE, 2015;175(10):1662-1669. A multicenter study was conducted ... regarding 249 goals-of-care conversations between 651 surrogate decision makers and 441 health care professionals in 13 intensive care units across the U.S. Of 457 surrogate decision makers, 355 (77.6%) endorsed religion or spirituality as fairly or very important in their life. Discussion of religious or spiritual considerations occurred in 40 of 249 conferences (16.1%). Surrogates were the first to raise religious or spiritual considerations in most cases (26 of 40). Their statements fell into the following main categories: 1) References to their religious or spiritual beliefs, including miracles; 2) Religious practices; 3) Religious community; 4) The notion that the physician is God's instrument to promote healing; and, 5) The interpretation that the end of life is a new beginning for their loved one. Some statements fell into more than 1 category. In response to surrogates' religious or spiritual statements, health care professionals redirected the conversation to medical considerations, offered to involve hospital spiritual care providers or the patient's own religious or spiritual community, expressed empathy, acknowledged surrogates' statements, or explained their own religious or spiritual beliefs. In only 8 conferences did health care professionals attempt to further understand surrogates' beliefs, for example, by asking questions about the patient's religion. http://archinte.jamanetwork.com/article.aspx?articleid=2430795&resultClick=3#Conclusions

Noted in Media Watch, 9 November 2015, #435 (p.16):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 3 November 2015 – '**A qualitative inquiry into the way doctors discuss spirituality.**' The authors describe a delicate, skilled, tailored process whereby physicians create a space in which patients feel safe enough to discuss intimate topics. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=10028620&fulltextType=RA&fileId=S1478951515001236

Noted in Media Watch, 17 August 2015, #423 (p.18):

- *PALLIATIVE MEDICINE* | Online – 12 August 2015 – '**Doctors discussing religion and spirituality: A systematic literature review.**' Religion and spirituality are discussed infrequently by physicians although frequency increases with terminal illness. Many prefer chaplain referral to discussing religion and/or spirituality with patients themselves. Discussions are facilitated by prior training and increased physician religiosity and spirituality. Insufficient time and training were the most frequently reported barriers. http://pmj.sagepub.com/content/early/2015/08/04/0269216315600912.abstract

Palliative care interventions for surgical patients: A systematic review

JAMA SURGERY | Online – 25 November 2015 – Despite the growth in attention to palliative care (PC), evidence substantiating its usefulness in surgery is sparse. Although most studies reported positive findings, the evidence was inconsistent, and many studies were small and did not measure the outcomes they intended to achieve, such as goal-concordant care. In the absence of data from high-quality research, the role of PC in improving surgical practice remains poorly defined. More work is needed to demonstrate which surgical patients most benefit from PC and how PC should be delivered. http://archsurg.jamanetwork.com/article.aspx?articleid=2470903

Noted in Media Watch, 6 October 2014, #378 (p.12):

- *JAMA SURGERY* | Online – 24 September 2014 – '**Use of palliative care and hospice among surgical and medical specialties in the Veterans Health Administration.**' In the Veterans Health Administration population, surgical patients are less likely to receive either hospice or palliative care (PC) in the year prior to death compared with medical patients, yet surgical patients have a longer length of time in these services. http://archsurg.jamanetwork.com/article.aspx?articleid=1906152

Hospitalisations at the end of life in four European countries: A population-based study via epidemiological surveillance networks

JOURNAL OF EPIDEMIOLOGY & COMMUNITY HEALTH | Online – 19 November 2015 – There is a paucity of cross-national population-based research on hospitalisations of people at the end of life. The authors compared in four European countries [i.e., Belgium, The Netherlands, Italy, and Spain], the frequency, time, length of and factors associated with hospitalisations in the last three months of life. The use of hospitals at the end of life increased over the last weeks of life of patients in all countries studied, but remained lowest in The Netherlands, as did the rate of readmissions. This may be due to gatekeeping by general practitioners who are trained and supported in preventing hospital readmissions at the end of life. http://jech.bmj.com/content/early/2015/11/19/jech-2015-206073.abstract

Noted in Media Watch, 5 October 2015, #430 (p.13):

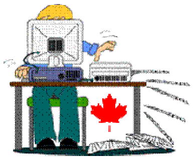
- *PLOS ONE* | Online – 24 July 2015 – **'Involvement of a case manager in palliative care reduces hospitalisations at the end of life in cancer patients: A mortality follow-back study in primary care.'** The GP is more likely to know preferred place of death, the place of death is more likely to be at the home, and less likely to be the hospital, and there are fewer hospitalisations in the last 30 days of life, when cancer patients receive additional support from a case manager compared with patients receiving standard GP care. http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0133197

Noted in Media Watch, 11 March 2015, #401 (p.11):

- *PLOS ONE* | Online – 10 March 2015 – **'How could hospitalisations at the end of life have been avoided? A qualitative retrospective study of the perspectives of GPs, nurses and family carers.'** Five key themes that could help avoid hospitalisation at the end of life emerged: 1) Marking the approach of death, and shifting the mindset; 2) Being able to provide acute treatment and care at home; 3) Anticipatory discussions and interventions to deal with expected severe problems; 4) Guiding and monitoring the patient and family in a holistic way through the illness trajectory; 5) Continuity of treatment and care at home. http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0118971

From acute palliation to chronic care: Using the narratives of two gay caregivers to explore experiences of providing HIV support across socio-historical contexts

JOURNAL OF GAY & LESBIAN SOCIAL SERVICES, 2015;27(4):482-501. Despite the longstanding shift in conceptualizing HIV/AIDS as a site of chronic care, versus one of acute palliation, few attempts have been made to examine caregiving in the context of this change. This study constitutes a preliminary attempt at exploring the evolving nature of HIV/AIDS caregiving among sexual minorities, primarily by comparing the narratives of two partnered caregivers of HIV-positive gay men whose stories are located in disparate socio-historical contexts. Whereas one caregiver provided support during an era in which HIV/AIDS was primarily conceptualized as acutely life-limiting, the other did so in the contemporary period of chronic HIV care. Although similarities are noted across the stories, distinctions are also apparent in how the caregivers encounter expressions of homophobia and HIV stigma, and negotiate these realities distinctly as a function of socio-historical context. http://www.tandfonline.com/doi/full/10.1080/10538720.2015.1085346



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://www.ipcrc.net/barry-r-ashpole.php

Medical student training on code status discussions: How far have we come?

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 November 2015 – Despite increased attention on the importance of physicians' communication with patients, including surrounding end-of-life care, students at many top medical schools continue to feel underprepared and under confident to engage in code status discussions with their patients... The authors obtained surveys from 56 students from 32 medical schools [in the U.S.]... The students had varying experience observing and conducting code status discussions, infrequently received guidance or feedback on these discussions, and did not know guidelines for best practices surrounding the conversations. Despite reporting moderate self-confidence with these conversations, most felt they required at least partial supervision conducting them; all requested further formal instruction. http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0125

Noted in Media Watch, 23 December 2013, #337 (p.13):

- *MEDICAL EDUCATION*, 2014;48(1):59-66. **'Palliative care education in U.S. medical schools.'** U.S. medical school surveys reveal varied and uneven approaches – from 2 hours in the classroom on end of life to weeks of palliative care (PC) training or hospice-based clinical rotations. PC competencies are too complex and universally important to be relegated to a minimum of classroom time, random clinical exposures... Given the reality of strained medical school curricula, developmentally appropriate, basic PC competencies should be defined and integrated into each year of the medical school curriculum... http://onlinelibrary.wiley.com/doi/10.1111/medu.12292/abstract;jsessionid=2FBCD9A6EFEAB3DC99DF08C1D05F1770.f04t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false

Noted in Media Watch, 9 December 2013, #335 (p.11):

- *JOURNAL OF PALLIATIVE CARE & MEDICINE* | Online – 5 December 2013 – **'Learning and teaching palliative care: Can we do better?'** Can we be sure that we are giving enough attention to learning and teaching of palliative care (PC)? Twenty years ago, James and MacLeod identified a number of aspects of PC education that were problematic.[1] http://www.omicsgroup.org/journals/Learning-and-Teaching-Palliative-Care-Can-We-Do-Better-2165-7386.1000e124.pdf

    1. 'The problematic nature of education in palliative care,' *Journal of Palliative Care*, 1993;9(4):5-10. There are many aspects of palliative care (P) that are problematic: 1) Lack of a long tradition and adequate conceptualization of PC; 2) Significance of psychological, emotional, and spiritual aspects; 3) Importance of but inadequate understanding of symptom control; 4) Fact that PC is not curative in the accepted sense; 5) Its multi-professional nature; 6) Range of different settings of PC; and, 7) PC caregivers have to perform their duties in situations where the emotional and psychological demands on them may be immense. http://www.ncbi.nlm.nih.gov/pubmed/7510805

U.S. National Perinatal Association

Recommendations for palliative and bereavement care in the NICU: A family-centered integrative approach

JOURNAL OF PERINATOLOGY, 2015;35:S19-S23. Technological advances have increased our ability to detect a life-threatening, life-limiting or lethal problem early in pregnancy, leaving parents months to anticipate a death or a prematurely born infant. Babies can also be born with unanticipated problems that could lead to death. In either scenario, perinatal palliative care (PC) should be offered as a strategy for family support. Since the preponderance of professional training focuses on saving lives, many health professionals are uncomfortable with PC. This article's purpose is to define best practices for the provision of family-centered perinatal and neonatal PC and provision of support to bereaved families experiencing anticipated and unanticipated life-limiting conditions or death of their infant. An overview of core concepts and values is presented, followed by intervention strategies to promote an integrated family-centered approach to palliative and bereavement care. The concluding section presents evidence-based recommendations. http://www.nature.com/jp/journal/v35/n1s/pdf/jp2015145a.pdf

Cont.

Noted in Media Watch, 26 October 2015, #433 (p.14):

- *JOURNAL OF PERINATOLOGY* | Online – 22 October 2015 – '**Primary palliative care in the delivery room: Patients' and medical personnel's perspectives.**' Most delivery room staff do not report relevant signs of distress in dying neonates and providing palliative care (PC) was not named as a relevant care-related source of distress by medical personnel. Half of the study participants reported high degrees of caregiver's emotional distress in primary PC situations, identifying insecurity of how to communicate with parents and to provide emotional support as the most common source of distress. http://www.nature.com/jp/journal/vaop/ncurrent/full/jp2015127a.html

N.B. Selected articles on perinatal palliative care noted in past issues of Media Watch are listed in this issue of the weekly report.

Rural-urban differences in costs of end-of-life care for elderly cancer patients in the U.S.

JOURNAL OF RURAL HEALTH | Online – 20 November 2015 – The authors analyzed Medicare claims data for 175,181 elderly adults with lung, colorectal, female breast, or prostate cancer diagnosis who died in 2008. The end-of-life costs were quantified as total Medicare expenditures for the last 12 months of care including inpatient, outpatient, physician services, hospice, home health, skilled nursing facilities (SNF), and durable medical expenditure. On average, elderly cancer patients cost Medicare $51,273, $50,274, $62,815, and $50,941 in the last year for breast, prostate, colorectal and lung cancer, respectively. Rural patients cost Medicare about 10%, 6%, 8%, and 4% less on end-of-life care (EOLC) than their urban counterparts for breast, prostate, colorectal, and lung cancer, respectively. Rural cancer patients were less likely to use hospice and home health, more likely to use outpatient and SNF, and they cost Medicare less on inpatient and physician services and more on outpatient care conditional on service use. The lower Medicare spending on EOLC for the rural cancer patients suggests disparities based on place of residence. A future study that delineates the source of the rural-urban difference can help us understand whether it indicates inappropriate level of palliative care and find effective policies to reduce the urban-rural disparities. http://onlinelibrary.wiley.com/doi/10.1111/jrh.12160/abstract

Noted in Media Watch, 8 June 2015, #413 (p.15):

- *PALLIATIVE MEDICINE* | Online – 3 June 2015 – '**Palliative care costs in Canada: A descriptive comparison of studies of urban and rural patients near end of life.**' [Drawing upon data from two prior studies] the mean total cost per patient was CAD$26,652 in urban areas, while it was CAD$31,018 in rural areas. The family assumed 20.8% and 21.9% of costs in the rural and urban areas, respectively. The rural families faced more costs related to prescription medication, out-of-pocket costs, and transportation, while the urban families faced more costs related to formal home care. http://pmj.sagepub.com/content/early/2015/06/03/0269216315583620.abstract

Who's in charge? The relationship between medical law, medical ethics, and medical morality

MEDICAL LAW REVIEW, 2015;23(4):505-530. Medical law inevitably involves decision-making, but the types of decisions that need to be made vary in nature, from those that are purely technical to others that contain an inherent ethical content. The authors identify the different types of decisions that need to be made and explore whether the law, the medical profession or the individual doctor is best placed to make them. They argue the law has failed in its duty to create a coherent foundation from which such decision-making might properly be regulated, and this has resulted in a haphazard legal framework that contains no consistency. The authors examine medico-legal topics in relation to these issues before ending by considering the risk of demoralisation. http://medlaw.oxfordjournals.org/content/23/4/505.abstract

Media Watch: Back Issues

Back issues of Media Watch are available on the International Palliative Care Resource Center website at:
http://www.ipcrc.net/archive-global-palliative-care-news.php

Integrating palliative care into the trajectory of cancer care

NATURE REVIEWS CLINICAL ONCOLOGY | Online – 24 November 2015 – Over the past five decades, palliative care (PC) has evolved from serving patients at the end of life into a highly specialized discipline focused on delivering supportive care to patients with life-limiting illnesses throughout the disease trajectory. A growing body of evidence informs the key domains in the practice of PC, including symptom management, psychosocial care, communication, decision-making and end-of-life care. Findings from multiple studies indicate integrating PC early in the disease trajectory can result in improvements in quality of life, symptom control, patient and caregiver satisfaction, illness understanding, quality of end-of-life care, survival, and costs of care. The authors discuss strategies to integrate oncology and PC by optimizing clinical infrastructures, processes, education, and research. The goal is to maximize patient access to PC and ... to improve patient outcomes. They provide a conceptual model for the integration of supportive and/or PC with primary and oncological care. The authors also discuss how health-care systems and institutions need to tailor integration based on their resources, size, and the level of primary PC available. http://scholar.google.ca/scholar_url?url=http://www.nature.com/nrclinonc/journal/vaop/ncurrent/full/nrclinonc.2015.201.html&hl=en&sa=X&scisig=AAGBfm3upYv85MX9CAT4ALyEEqNF07yW0g&nossl=1&oi=scholaralrt

Media Watch: Editorial Practice

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

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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5. 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.

Media Watch: Palliative Care Network-e Website

The website promotes education amongst health care providers in places around the world where the know-ledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. http://www.pcn-e.com/community/pg/file/owner/MediaWatch

Who wants to live forever? Living, dying and grieving in our digital society

SOCIAL SCIENCES | Online – 20 November 2015 – Almost ubiquitous hardware technology, such as smart phones, ensures that social networking sites are part of users' everyday norms and routines. However, some are now using these new communication technologies to deal with the issues of death, dying and grief. With the hope of being able to create digital memories to leave behind for future generations, the opportunity to "live on" and become digitally immortal is seen as empowering to some: but what about those left behind? Through a review of the current literature exploring how social media are being used as a new space to grieve and mourn, this paper contributes to the literature by arguing for the need for clarity in the lexicon being used by thanatologists and other disciplines. Furthermore, it introduces the term "digital zombie" to describe the dead who remain "alive" in our digital society. The paper concludes by joining the call for further research into the nascent phenomena being generated by human-computer interaction. http://www.mdpi.com/2076-0760/4/4/1127/htm

N.B. Click on 'Full-Text PDF' to access article.

Noted in Media Watch, 17 February 2014, #345 (p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2014;4(1):13-18. **'Palliative social media.'** The online world, in particular, is alive with discussions, comments and anecdotes about the topics of illness, disease, hospitals, death and dying. The topic of death and dying had in the not too distant past been seen as taboo, but willingness and need to talk openly about it appears to be on the increase. In parallel to this, many public awareness campaigns are highlighting society's need to be more prepared for dying and death. http://spcare.bmj.com/content/4/1/13.abstract

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/publications/newsletter/2015/11/media-watch/

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://www.ipcrc.net/archive-global-palliative-care-news.php

PALLIATIVE CARE NETWORK COMMUNITY: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

PALLIMED (Hospice & Palliative Medicine Blog): http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: http://aphn.org/category/media-watch/

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/updates/international-palliative-care-resource-center-media-watch/

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: http://palliativecarewa.asn.au/site/helpful-resources/ [Scroll down to 'International Websites' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report]

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: http://www.eapcnet.eu/Themes/Organization/Links.aspx [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes

U.K. | Omega, the National Association for End-of-Life Care: http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *ETHICS, MEDICINE & PUBLIC HEALTH* | Online – 19 November 2015 – **'Legalization of euthanasia in Quebec, Canada, as "medical aid in dying": A case study in social marketing, changing mores and legal manoeuvring.'** The adoption of the euphemism "medical aid in dying" to define the practice of euthanasia as a medical act was so that it would arguably be considered part of health care, which [in Canada] is under provincial jurisdiction... Also, the general public was more likely to accept a practice labelled "medical aid" than "euthanasia." The authors suggest that there is an ethical imperative for lawmakers to clearly inform the public about the explicit nature of what is being legalized. After passage of [Quebec's] Bill 52, the Supreme Court of Canada ... decreed in *Carter v. Canada* to legalize the practice of assisted suicide and/or euthanasia throughout Canada, and gave the Federal Government one year to establish guidelines. The Court differentiated between when there is no health care issue and when a person is suffering from a "grievous and irremediable medical condition." The authors contend that with assisted suicide, patients have greater freedom to change their minds free of social pressure and not complete their assisted suicide. In Between 1998 and 2012 36% of people in Oregon who received lethal medications for assisted suicide did not take the medications. http://www.sciencedirect.com/science/article/pii/S2352552515001656

N.B. *Ethics, Medicine & Public Health* recently posted several articles on the issue of assisted (or facilitated) death: http://www.journals.elsevier.com/ethics-medicine-and-public-health/recent-articles/

- *RESEARCH IN SOCIAL & ADMINISTRATIVE PHARMACY* | Online – 17 November 2015 – **'Aid-in-dying practice in Europe and the U.S.: Legal and ethical perspectives for pharmacy.'** This article briefly reviews "aid-in-dying" options such as euthanasia and physician-assisted suicide in Europe and the U.S. Current practices, medications used and statistics relating to prescription frequency and death rates from the participating States are briefly discussed. This paper also examines the role of pharmacists in assisted suicides, legal, ethical and professional challenges that they face, and future implications on pharmacist education to enable them to make an educated decision about their involvement in aid-in-dying practices. http://www.rsap.org/article/S1551-7411(15)00268-5/abstract

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