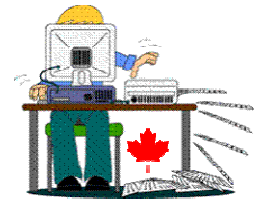


Media Watch...

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.

24 August 2015 Edition | Issue #424



Compilation of Media Watch 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

Promoting early intervention: Scroll down to [Specialist Publications](#) and 'The development of a framework to support bereaved children and young people: The Irish Childhood Bereavement Care Network' (p.10), in *Bereavement Care*.

Canada

First Nation's Peoples and end-of-life care

Lakehead University and Whitefish Bay partner for end-of-life care project

ONTARIO | *The Kenora Daily Miner & News* – 22 August 2015 – Whitefish Bay First Nation and Lakehead University are wrapping up a five-year program focused on end-of-life care. Maxine Crow, who worked alongside the project, said the partnership targeted a very important topic among First Nations in Northwestern Ontario. Crow said it was Lakehead University that approached Whitefish Bay First Nation about participating in the project. "It started with them as they approached our community and asked for permission from our leadership. Our leadership gave the approval and we had to approach our elders for their permission because palliative care is not something we talk about in our community," she said. "Our goal is just to honour our elders' wishes. If they want to avoid hospitalizations and admission, we want to honour their wishes. If they want to stay home as long as possible, we want to grant those wishes." The goal, Crow explained, is to be able to allow people who are chronically ill with an incurable disease to be able to stay home for as long as possible if they want. The First Nation also worked with the North West Health Integration Network (LHIN) to create a pilot project on how that end-of-life care program would function day-to-day. "We got funding from our local health integration network for a pilot project that ran over a nine-month period," Crow noted. Following the completion of the five-year project the pilot program with North West LHIN, Crow said the First Nation will look at acquiring funding and compiling information. <http://www.kenoradailyminerandnews.com/2015/08/22/lakehead-university-and-whitefish-bay-partner-for-end-of-life-care-project>

Noted in Media Watch, 2 December 2013, #334 (p.1):

- CTV NEWS | Online – 28 November 2013 – '**Aboriginal seniors face more health challenges, report...**' First Nations, Metis and Inuit of advancing years have poorer health than their non-aboriginal counterparts, but don't receive the same level of health-care services as other Canadian seniors.¹ <http://www.ctvnews.ca/health/aboriginal-seniors-face-more-health-challenges-report-suggests-1.1564234>

1. *Canada's Most Vulnerable: Improving Health Care for First Nations, Metis and Inuit Seniors*, The Health Council of Canada, November 2013. http://healthcouncilcanada.ca/rpt_det_gen.php?id=801&rf=2

Why employers are caring for the caregivers

THE GLOBE & MAIL | Online – 18 August 2015 – Brenda Hill has many identities. She works as a wealth adviser for BMO Nesbitt Burns... She's the primary caregiver for her 78-year-old mother, diagnosed five years ago with Alzheimer's disease. And she's the mother of two twenty-something kids. Yet it's a new role that has helped her cope with the stress of juggling it all: She's a participant in a five-year pilot program launched by Mount Sinai Hospital's Reitman Centre for Alzheimer's Support & Therapy ... to help employees caring for family members with the disease. This program and others like it are signs workplaces and policy makers are starting to take caregivers' needs more seriously. Last year, the federal government announced the Canadian Employers for Caregivers Plan, which called on a panel of employers for their suggestions about how to better support caregivers and keep them in the workplace.¹ A 2012 Confer-

ence Board of Canada study estimates the cost to employers in lost productivity because of caregiving responsibilities to be \$1.28-billion a year.² <http://www.theglobeandmail.com/report-on-business/careers/the-future-of-work/why-employers-are-caring-for-the-caregivers/article26000191/>

Specialist Publications

'Strategies for effective goals of care discussions and decision-making: Perspectives from a multi-centre survey of Canadian hospital-based health-care providers' (p.12), in *BMC Palliative Care*.

'Advance care planning: Let's start sooner' (p.12), in *Canadian Family Physician*.

1. 'Report from the Employer Panel for Caregivers – When Work and Caregiving Collide: How Employers Can Support Their Employees Who Are Caregivers,' Government of Canada, January 2015. [Noted in Media Watch, 26 January 2015, #394 (p.2)] <http://www.esdc.gc.ca/eng/seniors/reports/cec.shtml>
2. 'Home and Community Care in Canada: An Economic Footprint,' Conference Board of Canada, 2012. <http://www.conferenceboard.ca/cashc/research/2012/homecommunitycare.aspx>

N.B. See also 'Study: Caregivers in Canada, 2012,' data from the 2012 General Social Survey, Statistics Canada, 2013. <http://www.statcan.gc.ca/daily-quotidien/130910/dq130910a-eng.htm>

Noted in Media Watch, 8 December 2014, #387 (p.1):

- *THE FINANCIAL POST* | Online – 1 December 2014 – '**Don't make employees choose between their job and providing end-of-life care to a loved one.**' Job protection for those taking time off from work to provide end-of-life care for loved ones is guaranteed by both federal and provincial governments. A recent survey found that 59% of 692 organizations polled had formal compassionate care leave policies that recognize and accommodate employees' family and dependent care responsibilities for providing end-of-life care to loved ones.¹ <http://business.financialpost.com/2014/12/01/dont-make-employees-choose-between-their-job-and-providing-end-of-life-care-to-a-loved-one/>

1. 'Compassionate Care Policy,' Human Resources Professionals Association, October 2014. http://www.hrpa.ca/Documents/360/Compassionate_Care_Policy.pdf

N.B. See 'Guide to Balancing Work & Caregiving Obligations: Collaborative approaches for a supportive and well-performing workplace,' Canadian Human Rights Commission, 2014. [Noted in Media Watch, 16 June 2014, #362 (p.1)] http://www.chrc-ccdp.gc.ca/sites/default/files/a_guide_to_balancing_work.pdf

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.20.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 17 August 2015 – ‘**Doctors’ concerns about assisted death to inform debate at annual meeting.**’ The Canadian Medical Association (CMA) released results of a consultation with its members about the framework for providing physician-assisted death, an issue that continues to divide the country’s doctors.¹ Issues raised ... over the Supreme Court of Canada’s decision to overturn the ban on physician-aided death will form the basis of a debate among delegates at the CMA’s annual meeting ... next week. The CMA says results of that debate will provide input into both the federal panel struck to consult with Canadians on options to respond to the court’s decision and a newly formed provincial-territorial panel examining the issue. The most discussed issue ... was reconciling the rights of a doctor who chooses not to participate in assisted dying with the rights of an eligible patient to have access to the service. <http://www.theglobeandmail.com/news/national/doctors-concerns-about-assisted-death-to-inform-debate-at-annual-meeting/article25990492/>

Noted in Media Watch, 17 August 2015, #423 (p.3):

- CBC NEWS | Online – 14 August 2015 – ‘**Ontario forms expert panel on assisted dying.**’ The Ontario government is setting up an advisory group to study physician-assisted dying, leading 11 provinces and territories in examining the controversial subject. Ontario and the participating provinces and territories say the primary responsibility to provide health care resides with them... The panel will provide advice on development of policies, practices and safeguards for provinces and territories to consider when physician-assisted dying is legal within their respective jurisdictions. <http://www.cbc.ca/news/canada/toronto/ontario-forms-expert-panel-on-assisted-dying-1.3191186>

Noted in Media Watch, 20 July 2015, #419 (p.3):

- CBC NEWS | Online – 17 July 2015 – ‘**Doctor-assisted suicide panel includes original Crown witnesses.**’ The three-person panel to advise the federal government on doctor-assisted suicide includes two of the Crown’s witnesses in the original case that led to the landmark Supreme Court ruling. The federal government has named three academics, including an expert on palliative care, to lead consultations on how to respond to the Supreme Court ruling on doctor-assisted dying. The only direct consultations to be done by the panel, according to the government’s frequently asked questions, will be those who intervened in the Supreme Court case, as well as “relevant medical authorities.” The panel is to provide a final report to the ministers of justice and health by late fall. <http://www.cbc.ca/news/politics/doctor-assisted-suicide-panel-includes-original-crown-witnesses-1.3157361>

Specialist Publications

‘*Carter versus Canada: Effects on us and our profession*’ (p.19), in *Canadian Family Physician*.

1. ‘A Canadian Approach to Assisted Suicide: CMA Member Dialogue,’ Canadian Medical Association, 17 August 2015. https://www.cma.ca/Assets/assets-library/document/en/about-us/gc2015/canadian-approach-assited-dying_en.pdf



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>

U.S.A.

A racial gap in attitudes toward hospice care

THE NEW YORK TIMES | Online – 21 August 2015 – Hospice use has been growing fast in the U.S. as more people choose to avoid futile, often painful medical treatments in favor of palliative care and dying at home surrounded by loved ones. But the Harrises, who are African American, belong to a demographic group that has long resisted the concept and whose suspicions remain deep-seated ... an attitude borne out by recent federal statistics showing nearly half of white Medicare beneficiaries enrolled in hospice before death, compared with only a third of black patients. The racial divide is even more pronounced when it comes to advance care directives... Some 40% of whites aged 70 and over have such plans, compared with only 16% of blacks. Instead, black Americans – far more so than whites – choose aggressive life-sustaining interventions, including resuscitation and mechanical ventilation, even when there is little chance of survival. The racial gaps are expected to widen when Medicare is expected to begin

paying physicians in January 2016 for end-of-life counseling, and at a time when blacks and other minorities are projected to make up 42% of people 65 and over in 2050, up from 20% in 2000. http://www.nytimes.com/2015/08/25/health/a-racial-gap-in-attitudes-toward-hospice-care.html?_r=0

Specialist Publications

'The business case for palliative care: Translating research into program development in the U.S.' (p.15), in *Journal of Pain & Symptom & Pain Management*.

'African Americans and hospice care: A narrative analysis' (p.17), in *Narrative Inquiry in Bioethics*.

'Advance care planning discussions: Why they should happen, why they don't, and how we can facilitate the process' (p.13), in *Oncology*.

Related:

- NATIONAL PUBLIC RADIO | Online – 20 August 2015 – **'Can health care be cured of racial bias?'** Even as the health of Americans has improved, disparities in treatment and outcomes between white patients and black and Latino patients are almost as big as they were 50 years ago. A growing body of research suggests doctors' unconscious behavior plays a role in these statistics, and the Institute of Medicine of the National Academy of Sciences has called for more studies looking at discrimination and prejudice in health care.¹ <http://www.npr.org/sections/health-shots/2015/08/20/432872330/can-health-care-be-cured-of-racial-bias>

1. 'Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,' Institute of Medicine of the National Academy of Sciences, 2003. <http://www.nap.edu/catalog/12875/unequal-treatment-confronting-racial-and-ethnic-disparities-in-health-care>

Will we really be able to age in place?

OHIO | *Forbes* – 19 August 2015 – How will we access and pay for the support and services we'll need as we grow older? There is a growing sense of urgency around that question, as more of us are determined to remain as independent as possible throughout our lives. Many states are shifting away from requiring people who need long-term care to be in a nursing home in order to receive Medicaid. In Ohio, for example, nine out of 10 older people on Medicaid received long-term services in a nursing home in 1993; today, half that population receives such care at home, according to a study by the Scripps Gerontology Center at Miami University.¹ While that trend is welcome news, professionals in the field of aging say our system needs a huge course correction in order to adequately meet older people's desire to stay at home. <http://www.forbes.com/sites/nextavenue/2015/08/19/will-we-really-be-able-to-age-in-place/>

1. 'The road to balance: Two decades of progress in providing long-term services and supports for Ohio's older population,' Scholarly Commons, Miami University Libraries. (Accessed 19 August 2015) <http://dspace.lib.miamioh.edu/xmlui/handle/2374.MIA/5262>

Cont.

Related:

- PBS NEWSHOUR | Online – 18 August 2015 – **‘When patients live far from care, video conferencing can be a palliative support lifeline.’** People facing life-threatening illnesses often turn to palliative care, not only to address their pain, but also to navigate end-of-life choices. It’s never an easy process, but it’s even harder for those living in remote rural areas. One doctor in Northern California is finding innovative ways to help ease the burden. <http://www.pbs.org/newshour/bb/patients-live-far-care-video-conferencing-can-palliative-support-lifeline/>

Medicare says doctors should get paid to discuss end-of-life issues

KAISER HEALTH NEWS | Online – 18 August 2015 – Remember the so-called death panels? When Congress debated the Affordable Care Act in 2009, the legislation originally included a provision that would have allowed Medicare to reimburse doctors when they meet with patients to talk about end-of-life care. But then Sarah Palin argued that such payments would lead to care being withheld from the elderly and disabled. Her comment ignited a firestorm among conservatives and helped fuel the opposition to the legislation. Her assertions greatly distressed Dr. Pamelyn Close, a palliative care specialist in Los Angeles. “It did terrible damage to the concept of having this conversation,” she said. Amid the ensuing political uproar, Congress deleted the provision. And the lack of payments and concerns about the controversy further discouraged doctors from initiating these talks, according to Close. “We just are not having these conversations often enough and soon enough,” Close said. “Loved ones who are trying to do always the right thing, end up being weighed with tremendous guilt and tremendous uncertainty without having had that conversation.” When done right, according to Close, these counseling sessions often delve into end-of-life treatment options and legal documents, such as advance directives and living wills. The issues to be covered are complex and typically require a series of discussions. Right now, Medicare only pays doctors for this sort of advanced care planning if it happens during the first visit for new Medicare enrollees. But the government recently has again proposed Medicare reimburse doctors for including these conversations in their practice, whenever they occur. <http://khn.org/news/medicare-says-doctors-should-get-paid-to-discuss-end-of-life-issues/>

Related:

- MINNESOTA | *The Star Tribune* (Minneapolis) – 19 August 2015 – **‘Maplewood death shows critical need for end-of-life directive.’** A life-or-death decision by Maplewood paramedics, who stopped life support for an elderly woman at her husband’s insistence, underscores why individuals should have legal documents spelling out the care they want in what can be frantic and confusing end-of-life emergencies, health officials said... Paramedics and nursing home workers across Minnesota can relate to the difficult decision that was made ... when medics initially revived 71-year-old Linda Sandhei and started wheeling her to an ambulance, only to have the woman’s husband tell them to stop, according to a police report of the incident. Sandhei died soon after. Advance directives and do-not-resuscitate orders can provide clear guidance for such high-stress decisions. But absent those documents, medics are often asked to trust relatives who are distraught and may not know the wishes of their dying loved ones, said Dr. Jeffrey Ho, medical director for Hennepin County Medical Center’s emergency management services. <http://www.startribune.com/maplewood-death-shows-critical-need-for-end-of-life-directive/322354901/>
- *THE ATLANTIC* | Online – 18 August 2015 – **‘Whose job is it to talk to patients about death?’** In the U.S. health-care system, it’s often unclear who should talk to patients about end-of-life care options. Medicare’s new reimbursement scheme [due to take effect this fall] may incentivize doctors to take ownership of those difficult conversations. <http://www.theatlantic.com/health/archive/2015/08/palliative-care-medicare-end-of-life-ethics/400823/>



Tarzana hospital cites living will in attempt to remove Orthodox patient from life support: Children demand life-saving operation

CALIFORNIA | *The Jewish Journal* (Los Angeles) – 17 August 2015 – As David Stern, 61, an observant Orthodox Jew suffering from a rare neurodegenerative disease, lies conscious and hooked up to a respirator ... the hospital and lawyers for two of Stern's children are battling to determine whether the hospital should remove Stern from life support, as administrators say they are obligated to do, or perform a life-saving tracheostomy, as Stern's family demands. The dispute highlights a conflict at the intersection of modern medical ethics, Jewish medical ethics, civil law as it pertains to the validity of a living will, and the extent to which "quality of life" measures should impact whether a life-saving procedure is appropriate. http://www.jewishjournal.com/los_angeles/article/in_life_or_death_legal_dispute_modern_medical_ethics_jewish_law_and_civil_l

Noted in Media Watch, 20 October 2014, #380 (p.3):

- STATE OF NEW YORK | *Forward* – 15 October 2014 – '**The end-of-life battle over Jewish souls.**' The philosophy of dying a "good" death is anathema to many Orthodox Jews who believe that life should be sustained at all costs. Many Orthodox Jews ... believe that as long as the heart beats, the soul is alive. <http://forward.com/articles/207121/the-end-of-life-battle-over-jewish-souls/?p=all>

Noted in Media Watch, 4 October 2010, #169 (p.10):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2010;13(10):1267-1271. '**Caring for the dying patient from an Orthodox Jewish perspective.**' Care of the religious patient close to death is enormously complex especially when balancing religious obligations, the role of the rabbi, medical procedures, and personal preferences. These guidelines address ... profound issues such as the definition of death, organ donation, and caring for the patient at life's end. The guidelines can be useful for any hospital that serves an Orthodox Jewish population. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0088>

Expressions of loss and separation

Finally sharing my grief with my children

THE WASHINGTON POST | Online – 17 August 2015 – After my father's death, we mourned for 100 days, per Chinese custom. I stood beside my mom, brother and sister and received family and friends at our house. White barrettes pulled the hair off my face, leaving my emotions nowhere to hide. In many ways, mourning was something I had to get through and the 100 days gave me a timeline. One hundred days to fall apart. One hundred days to get to the other side of my heartache. My aunt said there was no rush to feel better, but I didn't want to linger in the pain that made my world spin under my feet. After those 100 days, I packed away my sorrow. I figured that if I could tuck it away, my grief wouldn't bleed into other areas of my life. If I could contain it, it wouldn't become a part of me. Once I adjusted to the reality of life without a father, there was no reason to think about his death, except for one day a year. A visit to his grave, flowers and dim sum. But as the years go

by, even this anniversary passes with less fanfare, especially since I moved to the East Coast. Each year, have the same conversation with my husband. "Do you know what tomorrow is?" <http://www.washingtonpost.com/news/parenting/wp/2015/08/17/finally-sharing-my-grief-with-my-children/>

Extract from *The Washington Post* article

I want to protect my kids from asking the hard questions I was forced to live through – the who, what, where, when, how and why of death. Especially the why. I don't want to re-open the door to my heartache. But grief is messy and spills over the edges, and it helps to have someone by your side when you need to clean up. My husband doesn't know how alone I felt on this day and on every other anniversary because I didn't tell him. By not sharing Dad with my family, I wasn't letting them know him or me.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE WASHINGTON POST* | Online – 19 August 2015 – ‘**Europe’s sinister expansion of euthanasia.**’ If you were a psychiatrist and a chronically depressed patient told you he wanted to die, what would you do? In Belgium, you might prescribe this vulnerable, desperate person a fatal dose of sodium thiopental. Between October 2007 and December 2011, 100 people went to a clinic in Belgium’s Dutch-speaking region with depression, or schizophrenia, or, in several cases, Asperger’s syndrome, seeking euthanasia. The doctors, satisfied that 48 of the patients were in earnest, and that their conditions were “untreatable” and “unbearable,” offered them lethal injection; 35 went through with it. These facts come not from a police report but an article by one of the clinic’s psychiatrists, Lieve Thienpont, in the British journal *BMJ Open*.¹ All was perfectly legal under Belgium’s 2002 euthanasia statute, which applies not only to terminal physical illness, still the vast majority of cases, but also to an apparently growing minority of psychological ones. Official figures show nine cases of euthanasia due to “neuropsychiatric” disorders in the two-year period 2004-2005; in 2012-2013, the number had risen to 120, or 4% of the total. Next door in The Netherlands, which decriminalized euthanasia in 2002, right-to-die activists opened a clinic in March 2012 to “help” people turned down for lethal injections by their regular physicians. In the next 12 months, the clinic approved euthanasia for six psychiatric patients, plus 11 people whose only recorded complaint was being “tired of living,” according to a report in ... *JAMA Internal Medicine*.² Bioethicists Barron H. Lerner and Arthur L. Caplan, who reviewed the data from the Low Countries in *JAMA Internal Medicine*, observe that the reports “seem to validate concerns about where these practices might lead.” https://www.washingtonpost.com/opinions/euthanasias-slippery-slope/2015/08/19/4c13b12a-45cf-11e5-8ab4-c73967a143d3_story.html

1. ‘Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: A retrospective, descriptive study,’ *BMJ Open*, 27 July 2015. [Noted in Media Watch, 3 August 2015, #421 (p.14)] <http://press.psprings.co.uk/Open/july/bmjopen007454.pdf>
2. ‘Comparison of the expression and granting of requests for euthanasia in Belgium in 2007 vs 2013,’ *JAMA Internal Medicine*, 10 August 2015. [Noted in Media Watch, 17 August 2015, #423 (p.12)] <http://archinte.jamanetwork.com/article.aspx?articleid=2426426>

International

End-of-life care in Finland

Insufficient training for palliative care professionals

FINLAND | Yle News – 22 August 2015 – Medical professionals who care for the dying must often make decisions based on their own intuition because their training doesn’t sufficiently prepare them for palliative care. It’s estimated that only one third of patients in Finland receiving end-of-life care get the specialised treatment they need. At the Kuhmo Nursing Home in the small Karelian town of Kuhmo near the Russian border, a pilot project is looking at how to fix this problem. Rauni Lipponon is the nursing home’s service supervisor. “It’s important to know what a patients’ needs and wishes are and how they want to be cared for at during their final days,” she says. The challenge with end-of-life care is that it often happens in a hospital or health centre ward – neither of which is equipped to provide for the needs of palliative care patients. While this Kuhmo pilot project won’t fix the problem of poor palliative care throughout the country, the hope is that it will start a discussion about how to improve it. For some who work in the field of palliative care, the biggest challenge is not medical care. “It’s dealing with the loved ones of the dying person by trying to respond to their sorrow, anxiety and need for information,” says practical nurse Arja Heikkinen. http://yle.fi/uutiset/insufficient_training_for_palliative_care_professionals/8246694

Cont.

Noted in Media Watch, 3 June 2013, #308 (p.12):

- *MORTALITY*, 2013;18(2):109-115. ‘**Death, dying and bereavement? Nordic perspectives.**’ The Nordic countries – Norway, Sweden, Denmark, Finland and Iceland – are a culture, geographical and historical entity. The countries vary widely in their own perspectives, but to an outsider, they may seem almost identical. The welfare state, cold climate, reticent people, gender equality, Lutheran confession and linguistic similarities give an impress of unit. Indeed, it would not be far-fetched to think that the Nordic countries have a lot in common when it comes to the culture on death and death rituals. This special issue of *Mortality* presents some viewpoints on death in the Nordic countries. Journal contents page: <http://www.tandfonline.com/toc/cmrt20/current>

Noted in Media Watch, 12 March 2012, #244 (p.5):

- FINLAND | YLE News – 11 March 2012 – ‘**Doctors want terminal care written into law.**’ Specialist doctors are calling for legislation that would mandate the provision of end-of-life care throughout Finland. They want to see a strong push in this direction as recommendations from the Ministry of Social Affairs & Health have failed to bring tangible results in public health services. About 300,000 of such patients ... are in need of palliative care... 15,000 require end-of-life care. Finland has about 60 doctors specialising in the field. The number of terminal care facilities can be counted on the fingers of one hand, which is nowhere near enough. Meanwhile the Health Ministry’s recommendations have not been incorporated in public health services. Half of the country’s hospital districts and large cities have been neglecting the matter, with many lacking even preliminary plans for terminal care provision. http://www.yle.fi/uutiset/news/2012/03/doctors_want_terminal_care_written_into_law_3324094.html

End-of-life care in Australia

Uptake of advance care planning increasing among providers

AUSTRALIA | *Australian Ageing Agenda* – 19 August 2015 – A national palliative care program for residential aged care is leading to an increase in advance care planning and the use of end-of-life care pathways and family conferences... The Palliative Approach Toolkit, a step-by-step framework for residential aged care facilities to implement palliative models of care, provides educational, clinical and management resources for staff, as well as resources for friends and family. The program ... has been rolled out nationally by the Department of Social Services. Professor Deborah Parker, director of the Centre for Applied Nursing Research (University of Western Sydney), led the development of the toolkit and will present on its evaluation at the Australian Palliative Care Conference in September. After implementing the toolkit, providers were more likely to engage residents and their families in palliative care conferences to discuss their future wishes – in 61% of cases, compared to 45% of cases prior to the toolkit, according to the audit. Providers were also 16% more likely to commence an end-of-life care pathway to refine the symptom management and care required in the final days or weeks of life, the evaluation found. <http://www.australianageingagenda.com.au/2015/08/19/uptake-of-advance-care-planning-increasing-among-providers/>

Noted in Media Watch, 23 March 2015, #402 (p.4):

- AUSTRALIA | ABC News – 20 March 2015 – ‘**Disadvantaged Australians missing out on end-of-life planning and care: Research.**’ Homeless and chronically mentally ill people are missing out on end-of-life planning and care, according to research commissioned by support service Footprints. The research highlights the cares of Australia’s most marginalised people. The research found homeless people living at boarding houses were at risk of being moved on if they were diagnosed with a terminal illness. <http://www.abc.net.au/news/2015-03-20/disadvantage-does-not-end-with-death/6336932>

Noted in Media Watch, 8 June 2015, #413 (p.9):

- *AUSTRALIAN HEALTH REVIEW* | Online – 1 June 2015 – ‘**Relinquishing or taking control? Community perspectives on barriers and opportunities in advance care planning.**’ There is a lack of awareness about advance care planning, compounded by issues in the accessibility of information, forms and support in completing the often complex documentation. Further, studies indicated health practitioners tend to avoid assisting patients with decision making and formalisation of their wishes for health care should they lose testamentary capacity. <http://www.publish.csiro.au/paper/AH14152.htm>

Home care in the U.K.

Could U.S.-style retirement villages spell the end of the care home?

U.K. | *The Daily Telegraph* – 17 August 2015 – Replacing traditional institutional care homes with new U.S. style retirement “villages” could help stem Britain’s looming “epidemic” of loneliness in old age, new research suggests. A study by the International Longevity Centre suggests pensioners living in special retirement communities are significantly less likely to feel lonely or isolated than those still living in their own homes. The research found that despite fears about moving into special accommodation, those who did so were more likely to feel that they had “control” over their lives than those of the same age in the wider population ... [adding] ... weight to calls for a radical rethink of provision of housing for older people to meet the needs of an ageing population. <http://www.telegraph.co.uk/news/health/elder/11803577/End-of-the-care-home.html>

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

Plans to improve referrals to palliative care in Yorkshire

U.K. (England) | *The Harrogate Informer* – 17 August 2015 – The Harrogate charity [Yorkshire Cancer Research] will study the records of more than 6,000 patients who died from cancer in Leeds in order to determine the best time for patients to be referred to palliative care and identify which elements contribute most to their quality of life. Previous research ... shows that 30% of people who die from cancer in the city receive no palliative care at all, and those who do gain access receive it an average of just six weeks before their death. Studies also suggest inequalities in access to palliative care services, with a wide variation in the timing of referrals across the region. Most patients with advanced cancer prefer to die at home, but the number of people who do so in Yorkshire is below the national average. Patients are more than twice as likely to die at home if they are engaged with specialist palliative care. <http://www.harrogate-news.co.uk/2015/08/17/plans-to-improve-referrals-to-palliative-care-in-yorkshire/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | Breitbart – 21 August 2015 – ‘**Assisted suicide becomes more widespread wherever introduced...**’ A review of the evidence on assisted dying has found “common patterns” indicating that the practice becomes more widespread and routine where introduced.¹ The report lends credence to fears that introducing legislation to allow for assisted dying in some instances creates a slippery slope to the practice being adopted in non-terminal cases. The report ... examined available evidence from The Netherlands, Belgium, Luxembourg, Switzerland, Oregon and Washington, all of which have legalised euthanasia or physician assisted suicide. <http://www.breitbart.com/london/2015/08/21/slippery-slope-assisted-suicide-becomes-more-widespread-wherever-introduced-report-confirms/>

1. ‘Assisted Suicide and Euthanasia: A Guide to the Evidence,’ Anscombe Bioethics Centre (Oxford, U.K.), August 2015. <http://www.bioethics.org.uk/evidenceguide.pdf>

- MALTA | *Malta Today* – 17 August 2015 – ‘**Doctors get requests for euthanasia, study finds.**’ An outright majority of Malta’s general practitioners are opponents of euthanasia, but a survey of 160 doctors has revealed that over 14% of them received requests for euthanasia from their ailing patients. A study ... carried out by Dr. Jurgen Abela from the University of Malta’s department of family medicine, surveyed general practitioners on their views on end of life ethics and the dilemma of giving dying patients a dignified death.¹ The 160 GPs interviewed revealed that they were believers in preserving life and would only consider intensifying painkillers to alleviate the pain of the dying. The GPs interviewed were shown to be in the main believers in preserving life, and while they would not consider euthanasia, many do not shun the intensification of painkillers and analgesia at patients’ end of life. http://www.maltatoday.com.mt/news/national/56181/doctors_get_requests_for_euthanasia_study_finds#.VdHwUs9RGot

1. ‘GPs and end-of-life decisions: Views and experiences,’ *Malta Medical Journal*, 2015;27(2):31-36. <http://www.um.edu.mt/umms/mj/showpdf.php?article=481>

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

The development of a framework to support bereaved children and young people: The Irish Childhood Bereavement Care Pyramid

BEREAVEMENT CARE, 2015;34(2):43-51. Children's bereavement poses a challenge not only for children themselves but for the families, communities, volunteers and professionals who support them. The Irish Childhood Bereavement Network set out to develop a framework to provide a comprehensive guide for children's bereavement support. The model is based on contemporary literature, existing policy and the views of professions, volunteers and parents. The process resulted in the 'Irish Childhood Bereavement Care Pyramid.'¹ The major pillars of children's needs, support/service responses and staff competencies are described at four levels, basic up to complex. The aim of the Pyramid is to guide adults to ensure that children are provided with the information and reassurance they need around a bereavement, to promote early intervention as appropriate and to recognise those few children who need specialist support to learn to live with their bereavement. Family context and the child's changing developmental status are emphasised as core considerations. <http://www.tandfonline.com/doi/abs/10.1080/02682621.2015.1063857#.VdMyus9RGos>

1. 'The Irish Childhood Bereavement Care Pyramid: Guide to support for bereaved children and young people' (2014) <http://www.childhoodbereavement.ie/wp-content/uploads/2014/10/ICBN-28pp-Report-PRINT.pdf>

N.B. The Irish Childhood Bereavement Care Network: <http://www.childhoodbereavement.ie/>

End-of-life care in Australia

Qualitative evaluation of a hospital bereavement service: The perspective of grieving adults

BEREAVEMENT CARE, 2015;34(2):69-75. The aim of this study was to evaluate the impact of an Australian Hospital Bereavement Service on the next of kin of deceased patients. The service provides three consecutive tiers of support to palliative care patients and families including information and compassion, non-specialised bereavement support and specialist intervention referral to external agencies on an individual and selective basis. Major themes identified were personal experience of grief; revisiting the hospital; and, bereavement care experiences. A suite of appropriate bereavement services, support groups, and feedback opportunities are perceived as helpful by grieving adults. This research also highlighted how difficult it is for some family members to return to the hospital following the death of their loved one. <http://www.tandfonline.com/doi/abs/10.1080/02682621.2015.1064582#.VdM0gc9RGos>



Children & Youth Grief Network: Region of Peel (Ontario, Canada)



Support Services for Grieving or Bereaved Children – Literature Search (annotated): <http://hearhouseospice.com/wp-content/uploads/2014/08/ChildrenandYouthCollaborativeFinalLiteratureSearch.pdf>

This literature search, international in scope, focuses on key articles, reports, etc., published between 2010 and 2015. Those listed reflect current thinking on the many different aspects of grief and bereavement among children and young people

Helplines, Online Support, Social Media – Supplement to Literature Search (annotated): <http://hearhouseospice.com/wp-content/uploads/2014/08/ChildYouthGriefCollaborativeLitFINALAp15.compressed.pdf>

Cont.

Noted in Media Watch, 17 August 2015, #423 (p.16):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 14 August 2015 – ‘**Adding value to palliative care services: The development of an institutional bereavement program.**’ The authors describe the development of the program at Dana-Farber Cancer Institute where they conceptualized bereavement services as a preventive model of care. Bereavement programs can both help bereaved individuals adapt to their loss and also positively impact hospitals by enhancing the reputation of the hospital within the community and providing an avenue for identifying opportunities for improvement in care processes. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0080>

Noted in Media Watch, 17 November 2014, #384 (p.11):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 November 2014 – ‘**An evaluation of a bereavement program in a U.S. research hospital.**’ The Bereavement Program at the National Institutes of Health Clinical Center [Bethesda, Maryland] makes contact with the next of kin on four occasions post-notification of death. The objective of this analysis was to evaluate the program’s effectiveness... <http://ajh.sagepub.com/content/early/2014/11/04/1049909114557538.abstract>

Related:

- *BEREAVEMENT CARE*, 2015;34(2):59-68. ‘**Identifying levels of vulnerability in grief using the Adult Attitude to Grief scale: From theory to practice.**’ The Range of Response to Loss model (RRL) and Adult Attitude to Grief scale (AAG) have evolved as practice tools able to profile the variable nature of client grief by identifying the initially instinctive reactions to loss alongside more aware coping responses. This paper describes the theoretical concepts which underpin the AAG, and recent research which confirms the factor structure of the scale and its capacity to identify varied levels of vulnerability. The application of the AAG as an assessment/outcome tool and guide to intervention are set out and future developments such as potential inclusion in the CORE IMS discussed. <http://www.tandfonline.com/doi/abs/10.1080/02682621.2015.1063859#.VdM1rc9RGos>

Advance care planning: Between tools and relational end-of-life care?

BMJ SUPPORTIVE & PALLIATIVE CARE, 2015;5(3):216-217. Reviews of care at the end of life have highlighted that people are concerned about how they are treated (or not) as persons at the end of life, including the importance of recognising and accommodating the perspectives and needs of those related to and caring for them. The concerns expressed in these reviews suggests that relational care is often lacking, in part due to “poor communication” about the dying process. This is not just about adding “family” to the list of those who need to be consulted about end-of-life care decision-making, although doing so may be relevant. Relational care is about finding ways to connect to people, and enabling them to continue to be part of and, perhaps, forge new, meaningful relationships. A focus on tools and protocols may help reframe how we think about caring for the dying, and even healthcare more broadly, but they in themselves are neither care nor valid indicators of end-of-life care, if we accept the importance that service users attribute to relational aspects of their care. <http://spcare.bmj.com/content/5/3/216.full>

Related:

- *BMC GERIATRICS* | Online – 19 August 2015 – ‘**End-of-life care communications and shared decision-making in Norwegian nursing homes – experiences and perspectives of patients and relatives.**’ Few patients and relatives [i.e., study participants] had participated in conversations about end-of-life care. Most relatives wanted such conversations, while the patients’ opinions varied. With some exceptions, patients and relatives wanted to be informed about the patient’s health condition. The majority wanted to be involved in the decision-making process, but leave the final decisions to the health professionals. Among the patients, the opinion varied; some patients wanted to leave the decisions more or less completely to the nursing home staff. Conversations about end-of-life care issues are emotionally challenging, and very few patients had discussed these questions with their family. The relatives’ opinions of the patient’s preferences were mainly based on assumptions; they had seldom talked about this explicitly. Both patients and relatives wanted the staff to raise these questions. <http://www.biomedcentral.com/content/pdf/s12877-015-0096-y.pdf>

Cont.

- *BMC PALLIATIVE CARE* | Online – 19 August 2015 – ‘**Strategies for effective goals of care discussions and decision-making: Perspectives from a multi-centre survey of Canadian hospital-based healthcare providers.**’ Overall, our findings suggest that enhancing patient and family involvement, communication between patients, families and healthcare providers, interprofessional collaboration, educational initiatives, and resource availability may improve discussions and decision-making about goals of care for medical interventions among seriously ill patients in hospital. Ongoing developments in these areas may be facilitated by a range of promising interventions, such as internet-based or video decision aids for advance care planning and goals of care determination, family meetings, teamwork training, societal and healthcare provider educational interventions, and quality improvement initiatives. <http://www.biomedcentral.com/content/pdf/s12904-015-0035-x.pdf>

- *CANADIAN FAMILY PHYSICIAN*, 2015;6(8):663-665. ‘**Advance care planning: Let’s start sooner.**’ Advance care planning (ACP) is a communication process wherein people plan for a time when they cannot make decisions for themselves. It includes reflection, deliberation, and determination of a person’s values and wishes or preferences for treatments at the end of life. Advance care planning should also include communication between an individual and his or her loved ones, future substitute decision makers (SDMs), and health care providers about these values and wishes. Evidence supports the effectiveness of ACP to improve the end-of-life experiences of patients and families. Despite the known benefits of ACP, often people with life-limiting illnesses facing an acute health crisis have not spoken up about their preferences. <http://www.cfp.ca/content/61/8/663.full>

- *JOURNAL OF AGING & HEALTH* | Online – 17 August 2015 – ‘**Shared decision-making in nursing homes: Factors associated with the empowerment of direct care workers.**’ Shared decision-making may be enhanced where nurse management shares relevant information with the DCWs (direct care workers), listens to their ideas, provides explanations when DCWs suggestions are not used, and does so in a supportive environment. Organizational characteristics of importance [identified in this study] include linking wages to DCWs performance and providing an accessible training program. <http://jah.sagepub.com/content/early/2015/08/14/0898264315600689.abstract>

Cont. next page

[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 and research 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.

[Links to Sources](#)

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
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.

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 19 August 2015 – ‘**Differences in physicians’ verbal and non-verbal communication with black and white patients at the end of life.**’ In this small regional sample, hospital-based physicians [in western Pennsylvania] have similar verbal communication behaviors when discussing end-of-life care for otherwise similar black and white patients, but exhibit significantly fewer positive, rapport-building non-verbal cues with black patients. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00402-9/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00402-9/abstract)
- *ONCOLOGY*, 2015;15;29(8). ‘**Advance care planning discussions: Why they should happen, why they don’t, and how we can facilitate the process.**’ Half to three-quarters of patients with incurable cancer think that they might be cured by chemotherapy, radiation, or surgery. The source of this denial may lie with them, it may be traceable to their physicians, or it may be a combination of the two. This avoidance has consequences, since those patients with “prognostic awareness” have end-of-life care pathways that involve little use of the hospital, ICU, end-of-life chemo, or “codes” with almost no chance of success, and much more dying at home with hospice care. If we can successfully initiate advance care planning discussions with our patients and families, their end-of-life processes will improve, resulting in better care, less use of the hospital, and more honoring of newly discerned choices. The authors show how this can be done in regular oncology practice by introducing the Johns Hopkins “Palliative Care Temporary Tattoo” and by providing some ways to discuss cardiopulmonary resuscitation in settings where it will not be helpful. <http://www.ncbi.nlm.nih.gov/pubmed/26281841>
- *PALLIATIVE MEDICINE* | Online – 20 August 2015 – ‘**Does facilitated advance care planning reduce the costs of care near the end of life? Systematic review and ethical considerations.**’ Looking at the impact of advance care planning on costs raises delicate ethical issues. Given the increasing pressure to reduce expenditures, there may be concerns that cost considerations could unduly influence the sensitive communication process, thus jeopardising patient autonomy. Safeguards are proposed to reduce these risks. The limited data indicate net cost savings may be realised with advance care planning. <http://pmj.sagepub.com/content/early/2015/08/20/0269216315601346.abstract>
- *PALLIATIVE MEDICINE* | Online – 17 August 2015 – ‘**A multi-method analysis of shared decision-making in hospice interdisciplinary team meetings including family caregivers.**’ Much of the existing research on shared decision-making in hospice and palliative care focuses on the provider-patient dyad; little is known about shared decision-making that is inclusive of family members of patients with advanced disease. Shared decision-making occurred infrequently in hospice interdisciplinary team meetings that included family caregivers. Barriers to shared decision-making included time constraints, communication skill deficits, unaddressed emotional needs, staff absences, and unclear role expectations. The hospice philosophy of care, current trends in healthcare delivery, the interdisciplinary nature of hospice teams, and the designation of a team leader/facilitator supported shared decision-making. <http://pmj.sagepub.com/content/early/2015/08/12/0269216315601545.abstract>

End-of-life care in South Korea

Terminal versus advanced cancer: Do the general population and health care professionals share a common language?

CANCER RESEARCH & TREATMENT | Online – 10 August 2015 – Many end-of-life care studies are based on the assumption that there is a shared definition of language concerning the stage of cancer. However, studies suggest that patients and their families often misperceive patients’ cancer stages and prognoses. Discrimination between advanced cancer and terminal cancer is important because the treatment goals are different. The authors evaluated the understanding of the definition of advanced versus terminal cancer of the general population and determined associated socio-demographic factors. Only 411 (20.6%) [of 2,000] respondents chose “advanced,” while most respondents (74.5%) chose “terminal stage” as the stage of the hypothetical patient, and a small proportion of respondents chose “early stage” (0.7%) or “don’t know” (4.4%). Continuous effort is required in order to establish common and shared definitions of the different cancer stages and to increase understanding of cancer staging for the general population. <http://e-crt.org/journal/view.php?doi=10.4143/crt.2015.124>

Cont.

Noted in Media Watch, 14 October 2013, #327 (p.9):

- *CRITICAL CARE* | Online – 4 October 2013 – ‘**Survey of controversial issues of end-of-life treatment decisions in Korea: Similarities and discrepancies between healthcare professionals and the general public.**’ Over 50% of survey respondents thought that end-of-life treatment decisions should be made through discussions between the physician and the patient’s family. For conflict resolution, 75% of South Koreans not working in healthcare preferred direct settlement between the medical staff and the patient’s family, while 55% of healthcare professionals preferred the hospital ethics committee. <http://ccforum.com/content/pdf/cc13042.pdf>

Moral distress in pediatric intensive care

JAMA PEDIATRICS | Online – Accessed 17 August 2015 – Moral distress is the term increasingly used by health care professionals to name the angst they experience when they feel unable to practice as they should. In a moral dilemma, a professional must choose between competing potential actions; in moral distress, the professional has decided what the right action is but cannot make it happen owing to internal or external constraints ... e.g., inadequate staffing, not enough beds, other health care professionals’ influence, family or patient choices, administrative agendas, institutional policies, and legislation. Moral distress can manifest as anger, frustration, shame, or a sense of impotence and may be accompanied by physical reactions. Perception, however, is still key to understanding this experience; facing the same circumstances, one health care professional may believe, for example, that extending life-sustaining treatment as a time-trial is the right choice while another professional may find it unacceptable and push for immediate withdrawal of such treatment. Either professional may experience moral distress depending on the course chosen or the degree to which the professional feels complicit in making the “wrong” choice. Undoubtedly, the so-called right thing to do is many

times a personal and subjective concept. How can we deal with such a conundrum? The objective of this article is not only to raise awareness of moral distress as an important issue in the pediatric intensive care unit but also suggest some strategies to resolve or minimize it. <http://archpedi.jamanetwork.com/article.aspx?articleid=2411825>

The transformation process for palliative care professionals: The metamorphosis, a qualitative research study

PALLIATIVE MEDICINE | Online – 17 August 2015 – During their professional activity, palliative care professionals go through a series of phases, depending on the relationship between the cost of caring and the satisfaction of caring, which can influence both the care provided to patients and families and their own personal circumstances. Being aware of this risk, and implementing self-care strategies, can protect professionals and enable them to conduct their work... Reflecting on the experiences of these professionals could be useful for other health professionals. <http://pmj.sagepub.com/content/early/2015/08/12/0269216315583434.abstract>

Noted in Media Watch, 28 July 2014, #368 (p.6):

- *ADVANCES IN NEONATAL CARE* | Online – 11 July 2014 – ‘**The relationship between providing neonatal palliative care and nurses’ moral distress: An integrative review.**’ The neonatal intensive care unit has frequent situations in which moral distress may occur including providing palliative care. http://journals.lww.com/advancesinneonatalcare/Abstract/publishahead/The_Relationship_Between_Providing_Neonatal.99981.aspx

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

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

Roma women's perspectives on end-of-life decisions

JOURNAL OF BIOETHICAL INQUIRY | Online – 18 August 2015 – Spain's Roma community has its own cultural and moral values. These influence the way in which end-of-life decision-making is confronted. [In this study] the authors considered age and care role to be the variables that can have the most influence on opinion regarding end-of-life decision-making. The main ideas gleaned from the data were: 1) The important role of the family in end-of-life care, especially the role of women; 2) The large influence of community opinion over personal or family decisions, typical of closed societies; 3) The different preferences women had for themselves compared to that for others regarding desired end-of-life care and,; 4) Unawareness or rejection of advance directives. Roma women wish for their healthcare preferences to be taken into account, but "not in writing." The study concluded that the success of end-of-life healthcare in Roma families and of their involvement in the making of healthcare decisions depends upon considering and respecting their idiosyncrasy. <http://link.springer.com/article/10.1007/s11673-015-9656-2>

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

- *JOURNAL OF IMMIGRANT & MINORITY HEALTH* | Online – 25 October 2012 – '**Dying and death in some Roma communities: Ethical challenges.**' Five more important themes about the Roma people facing dying and death have been identified, the ... 1) Perception of illness in the community as reason for shame and the isolation that results from this, as well as the tendency for Roma people to take this on in their self image; 2) Importance of the family as the major support for the ill/dying individual, including the social requirement that family gather when someone is ill/dying; 3) Belief that the patient should not be told his/her diagnosis for fear it will harm him/her and that the family should be informed of the diagnosis as the main decision maker regarding medical treatment; 4) Reluctance of the Roma to decide on stopping life prolonging treatment; and, 5) View of death as "impure." By paying attention to and respecting the Roma patients' values, spirituality, and relationship dynamics, the medical staff can provide the most suitable healthcare by respecting the patients' wishes and expectations. <http://www.springerlink.com/content/f6494wu42j22427h/>

The business case for palliative care: Translating research into program development in the U.S.

JOURNAL OF PAIN & SYMPTOM & PAIN MANAGEMENT | Online – 19 August 2015 – Specialist palliative care often embraces a "less is more" philosophy that runs counter to the revenue-centric nature of most health care financing in the U.S. A special business case is needed in which the financial benefits for organizations such as hospitals and payors are aligned with the demonstrable clinical benefits for patients. Based on published studies and of the authors' work with palliative care programs over the past 15 years, they identified ten principles that together form a business model for specialist palliative care. These principles are relatively well established for inpatient palliative care, but are only now emerging for community-based palliative care. Three developments that are key for the latter are the increasing penalties from payors for over-utilization of hospital stays, the variety of alternative payment models such as Accountable Care Organizations, which foster a population health management perspective, and payor-provider partnerships that allow for greater access to and funding of community-based palliative care. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00399-1/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00399-1/abstract)

Different experiences and goals in different advanced diseases: Comparing serial interviews with patients with cancer, organ failure, or frailty and their family and professional carers

JOURNAL OF PAIN & SYMPTOM & PAIN MANAGEMENT, 2015;50(2):216-224. A detailed understanding of the varied experiences of people living and dying with different conditions and their family and professional caregivers should help policymakers and clinicians design and deliver more appropriate and person-centered care. [This study] ... comprised 828 interviews with 156 patients, 114 family caregivers, and 170 health professionals. Narratives about cancer typically had a clear beginning, middle and an anticipated end. Cancer patients gave a well-rehearsed account of their illness, hoping for recovery alongside fear of dying. In contrast, people with organ failure and their family caregivers struggled to pinpoint

Cont.

when their illness began, or to speak openly about death, hoping instead to avoid further deterioration. Frail older people tended to be frustrated by their progressive loss of independence, fearing dementia or nursing home admission more than dying. These contrasting illness narratives affect and shape the experiences, thoughts, and fears of patients and their carers in the last months of life. Palliative care offered by generalists or specialists should be provided more flexibly and equitably, responding to the varied concerns and needs of people with different advanced conditions. [http://www.jpsmjournal.com/article/S0885-3924\(15\)00153-0/abstract](http://www.jpsmjournal.com/article/S0885-3924(15)00153-0/abstract)

Related:

- *NEW ENGLAND JOURNAL OF MEDICINE*, 2015;373(8):747-755. '**Palliative care for the seriously ill.**' This review summarizes trends and the focus of such care on communication, pain and symptom management, and psychosocial assessment. <http://www.nejm.org/doi/full/10.1056/NEJMra1404684>

Medical ethical principles may drive improvement of quality of dying in Hong Kong

JOURNAL OF PALLIATIVE CARE & MEDICINE | Online – 6 August 2015 – Population ageing raises concern regarding the quality of end-of-life care (EOLC), not only for people with cancer but for all dying of end stage chronic diseases, particularly for dementia. Medical ethical principles, legal and cultural factors affect the quality of end-of-life care. This article discusses how these currently contribute to EOLC in Hong Kong, in the context of differing trajectories of development in China, other Asian countries, and the U.S. EOLC for non-cancer patients has only recently been highlighted, where ethical, legal, and cultural issues are being debated. Although there is no statute or case law that directly govern the legal status of advance directives in Hong Kong, a validly made advance directive is generally recognized at common law. However, there is a range of other legal barriers to providing EOLC according to medical ethical principles. There is little discussion among health care providers or the public regarding advance directives, euthanasia, physician assisted suicide, or withdrawal of life support, particularly for those with dementia. <http://www.omicsgroup.org/journals/medical-ethical-principles-may-drive-improvement-of-quality-of-dying-in-hong-kong-2165-7386-1000227.pdf>

Does disclosure of terminal prognosis mean losing hope? Insights from exploring patient perspectives on their experience of palliative care consultations

JOURNAL OF PALLIATIVE MEDICINE | Online – 19 August 2015 – A primary barrier to physician disclosure of terminal prognosis is concern that patients will lose hope. Inpatient palliative care (IPC) teams are especially posed to mediate this barrier, but little is known about patient perceptions and experience of IPC. This study aimed to elicit seriously ill patients' perspective and experience of an IPC consultation, and to explore patient attitudes toward information derived from the consultation. An exploratory, qualitative study was conducted at a large non-profit community hospital in the Los Angeles area. An established IPC team conducted individualized consults with patients and families within 24 hours of referral. Twelve seriously ill patients were interviewed. Four themes were identified: 1) Holistic care approach; (2) Knowledge/information gained; 3) Hope and enlightenment; and, 4) Patient readiness. Results suggest that disclosure of a terminal prognosis does not mean loss of patient hope. Instead, hope was redefined on a goal other than cure. Presenting patients with information and increasing their knowledge about care options and resources may facilitate patients in identifying meaningful goals that are better aligned with their prognosis. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0038>

Noted in Media Watch, 16 March 2015, #401 (p.12):

- *PROGRESS IN PALLIATIVE CARE* | Online – 9 March 2015 – '**Palliative care professionals' evaluations of the feasibility of a hope communication tool: A pilot study.**' Palliative care professionals have recognized the importance of hope for their patients. However, they sometimes experience hope as a barrier for end-of-life communication, for instance when patients have unrealistic hope. A hope communication tool helped participants to reach depth and address end-of-life issues. <http://www.maneyonline.com/doi/abs/10.1179/1743291X15Y.0000000003>

Cont.

Noted in Media Watch, 27 October 2014, #381 (p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 October 2014 – ‘**How to communicate with patients about future illness progression and end of life: A systematic review.**’ Practices vary in how strongly [articles reviewed] encourage patients to engage in talk about matters such as illness progression and dying. Fishing questions and indirect talk make it particularly easy to avoid engaging – this may be appropriate in some circumstances. Hypothetical questions are more effective in encouraging on-topic talk, as is linking questions to patients’ cues. Shifting towards more “optimistic” aspects helps maintain hope but closes off further talk about difficulties: practitioners may want to delay doing so. <http://spcare.bmj.com/content/early/2014/10/24/bmjspcare-2014-000649.abstract>

Controversies in faith and health care

THE LANCET | Online – Accessed 17 August 2015 – Differences in religious faith-based viewpoints ... on the sanctity of human life, acceptable behaviour, health-care technologies and health-care services contribute to the widespread variations in health care worldwide. Faith-linked controversies include family planning, child protection (especially child marriage, female genital mutilation, and immunisation), stigma and harm reduction, violence against women, sexual and reproductive health and HIV, gender, end-of-life issues, and faith activities including prayer. Buddhism, Christianity, Hinduism, Islam, Judaism, and traditional beliefs have similarities and differences in their viewpoints. Improved understanding by health-care providers of the heterogeneity of viewpoints, both within and between faiths, and their effect on health care is important for clinical medicine, public-health programmes, and health-care policy. Increased appreciation in faith leaders of the effect of their teachings on health care is also crucial. This Series paper outlines some faith-related controversies, describes how they influence health-care provision and uptake, and identifies opportunities for research and increased interaction between faith leaders and health-care providers to improve health care. <http://www.sciencedirect.com/science/article/pii/S0140673615602525>

N.B. The *Lancet's* 2005 7-part series of Viewpoints explores contrasting end-of-life perspectives (i.e., Hindu, Islamic, Jewish, Buddhist, Christian, Catholic, and Humanist): <http://www.thelancet.com/series/end-of-life>

African Americans and hospice care: A narrative analysis

NARRATIVE INQUIRY IN BIOETHICS, 2015;5(2):151-165. Studies suggest terminally ill African Americans’ care is generally more expensive and of lower quality than of comparable non-Hispanic white patients. Scholars argue increasing hospice enrollment among African Americans will help improve end-of-life care for this population, yet few studies have examined the experiences of African American patients and their loved ones after accessing hospice care. The authors explore how African American patients and lay caregivers evaluated their hospice experiences. Drawing from interviews, they use a modified version of Bute & Jensen’s narrative typology to organize patients’ and caregivers’ stories into three general categories: 1) Narratives of satisfaction; 2) Narratives of regret; and, 3) Narratives of ambivalence. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/narrative_inquiry_in_bioethics/v005/5.2.dillon.html

Noted in Media Watch, 22 December 2014, #389 (p.16):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2014;10(4):338-355. ‘**Values important to terminally ill African American older adults in receiving hospice care.**’ While racial disparity in the use of hospice care by older African Americans is widely acknowledged, little is known about the values that they consider as important in receiving health care services along with direct experiences with having these values respected by hospice care providers: 1) Dying at home; 2) Open communications; 3) Independent decision-making; 4) Autonomy in daily life; 5) Unwillingness to be a burden; and, 6) Relationships. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2014.975317>

N.B. Additional articles on the underuse of hospice by African Americans living with a terminal illness noted in past issues of Media Watch are listed in this issue of the weekly report.

Cont.

Noted in Media Watch, 18 August 2015, #371 (p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 August 2014 – ‘**Barriers to employment of African American professionals in hospice: A qualitative study with African American social work students.**’ A major barrier to African American hospice utilization is the lack of African American hospice professionals. Barriers include a lack of hospice content in social work education, differences between African American cultural and religious beliefs and hospice philosophy, and that the lack of African American hospice patients resulted in a lack of desire for employment in hospice. Strategies for recruiting and retaining African American hospice social workers are proposed. <http://ajh.sagepub.com/content/early/2014/08/11/1049909114546543.abstract>

Implementation of a pilot telehealth programme in community palliative care: A qualitative study of clinicians’ perspectives

PALLIATIVE MEDICINE | Online – 19 August 2015 – Telehealth technologies are an emerging resource opening up the possibility of greater support if they have utility for patients, carers and clinicians. They may also help to meet health systems’ imperatives for improved service delivery within current budgets. Service providers considered telehealth as a means to augment current service provision in a complementary way rather than as a replacement for face-to-face assessments. This technology, however, challenged the team to critically explore aspects of current service provision. The introduction of technologies also has the potential to alter the dynamic of relationships between patients and families and community palliative care clinicians. <http://pmj.sagepub.com/content/early/2015/08/18/0269216315600113.abstract>

Evaluating the effects of mindfulness-based interventions for informal palliative caregivers: A systematic literature review

PALLIATIVE MEDICINE | Online – 17 August 2015 – A total of 13 articles, reporting 10 studies were included. All studies were conducted in the last 5 years. Dementia caregivers were the most frequently researched population. Results suggest that mindfulness-based interventions are feasible and acceptable to offer to informal palliative caregivers and may provide benefit, particularly in terms of reducing depression and caregiver burden and increasing quality of life. However, effects were not as robust as findings in the wider mindfulness intervention literature. This is the first systematic literature review on this topic. <http://pmj.sagepub.com/content/early/2015/08/12/0269216315600331.abstract>

Noted in Media Watch, 16 September 2013, #323 (p.8):

- *ANNALS OF FAMILY MEDICINE*, 2013;11(5):421-428. ‘**A multicenter study of physician mindfulness and health care quality.**’ Mindfulness refers to a person’s tendency to remain attentive to their own experience, thoughts and feelings. Over the past decade, it has been recommended that physicians enhance their own capacities for mindfulness when practicing medicine and interacting with patients. <http://www.annfammed.org/content/11/5/421/suppl/DC1>

Noted in Media Watch, 13 January 2014, #340 (p.13):

- *SOCIAL WORK* | Online – 1 January 2014 – ‘**Witness to suffering: Mindfulness and compassion fatigue among traumatic bereavement volunteers and professionals.**’ Because prior research suggests that compassion satisfaction may protect against compassion fatigue, the authors hypothesized a) Mindfulness would be positively correlated with compassion satisfaction; b) Mindfulness would be inversely correlated with compassion fatigue; and, c) There would be differences between respondents with a personal history of traumatic bereavement and those with no such history. <http://sw.oxfordjournals.org/content/early/2014/01/01/sw.swt044.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>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BRITISH JOURNAL OF MEDICINE & MEDICAL RESEARCH*, 2015;9(7):1-12. '**Arguments in support and against euthanasia.**' This paper explores and analyzes the arguments in support and against euthanasia and physician assisted suicide. For the purpose of this article ... 247 journal articles, book chapters and websites [were reviewed], and ... 74 references [are] cited in the manuscript. Euthanasia should be legally permissible if certain conditions are present: the patient is terminally ill, death is imminent and, treatment was appropriate and well. If a patient autonomously chooses to end his life or have someone else assist him in doing so, then it is morally permissible. Patient must be fully informed of the diagnosis and prognosis of an incurable, fatal disease, and competent to make the decision. <http://sciencedomain.org/abstract/10093>

N.B. To access full article click on PDF icon.

- *BRITISH MEDICAL JOURNAL* | Online – 20 August 2015 – '**Assisted dying – time for a full and fair debate.**' Next month the U.K. will decide whether or not to legalise assisted dying. Very different to the law in Belgium, the U.K. Assisted Dying Bill is based closely on the law in the U.S. state of Oregon, where assisted dying has been legal since 1997. The bill ... would allow mentally competent adults with a terminal illness and a prognosis of less than six months the possibility of an assisted death by self administration of prescribed drugs. Patients who request an assisted death would be reviewed by two doctors and subsequently by a High Court judge. The request would be granted only if all agree that the patient has a voluntary, clear, settled and informed wish to end their life. <http://www.bmj.com/content/351/bmj.h4517>
- *BRITISH MEDICAL JOURNAL* | Online – 19 August 2015 – '**Assisted dying: Law and practice around the world.**' Several countries in Europe and in North and South America [The Netherlands, Belgium, Luxembourg, Switzerland, U.S., Canada and Columbia] already allow doctors to help patients end their lives. Proponents and opponents do not all agree on the terminology used to describe the process. <http://www.bmj.com/content/351/bmj.h4481>
- *BRITISH MEDICAL JOURNAL* | Online – 19 August 2015 – '**Would judicial consent for assisted dying protect vulnerable people?**' The private members' bills presented [in the U.K.] by Charles Falconer and Rob Marris require a High Court judge to confirm decisions by doctors to approve assisted suicide. Jacky Davis thinks that this is sufficient to protect vulnerable people; Ilora Finlay does not. Jacky Davis, consultant radiologist, Whittington Hospital, London, is chair of Health Professionals for Assisted Dying, and member of BMA Council and BMA Medical Ethics Committee. Ilora Finlay, professor of palliative medicine, Cardiff University, is co-chair of Living & Dying Well and chair elect of National Council for Palliative Care, immediate past president of the British Medical Association BMA and member of BMA Medical Ethics Committee. <http://www.bmj.com/content/351/bmj.h4437>
- *CANADIAN FAMILY PHYSICIAN*, 2015;61(8):728. '**Carter versus Canada: Effects on us and our profession.**' The recent Supreme Court of Canada (SCC) ruling on *Carter versus Canada* and the upcoming changes in Quebec regarding physician-assisted dying are important examples of the dynamic nature of society's contract with our profession. In a unanimous decision, the SCC struck down the Criminal Code's absolute prohibition on providing assisted dying. Whereas the Quebec law is restricted to patients with terminal illness, the effect of the SCC's decision is broader: [Patients] must be competent adults who clearly consent to the termination of life, and have a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual. Most palliative care in Canada is provided by teams that include family physicians (both those providing comprehensive care and those with enhanced skills in this domain). Considerable work has been done reviewing these core and enhanced skills competencies. It is essential that together we – providers, policy makers, system planners – minimize the barriers and provide superb care to those nearing the end of life's journey. <http://www.cfp.ca/content/61/8/728.full>

N.B. French language version: <http://www.cfp.ca/content/61/8/727.full>. The College of Family Physicians of Canada have produced a 'Guide for Reflection on Ethical Issues Concerning Assisted Suicide and Voluntary Euthanasia' that will be released in the fall of 2015. This reflective document aims to assist physicians in understanding the changes in the law, the terminology, and the effects of legal changes on physicians.

Cont.

- *POLICY QUARTERLY* | Online – ‘**The ethics of active voluntary euthanasia and the related subject of physician assisted suicide.**’ The August 2015 issue of the journal of the Institute for Governance & Policy, University of Wellington, includes four articles on these topics: 1) ‘Aid in dying in the High Court: Seales vs. Attorney General,’ pp.27-29; ‘Physician-assisted dying,’ pp.30-33; ‘Euthanasia and assisted suicide good or bad public policy?’ pp.34-37; and, ‘The consequences of euthanasia legislation for disabled people,’ pp.38-40 <http://igps.victoria.ac.nz/publications/files/6f0896285a1.pdf>
- *SCIENCE & ENGINEERING ETHICS* | Online – 15 August 2015 – ‘**Aruna Shanbaug: Is her demise the end of the road for legislation on euthanasia in India?**’ Aruna Ramachandra Shanbaug breathed her last after 42 years of being in a persistent vegetative state. Euthanasia in any form is not permitted in India and it was only in the year 2011 that a petition was filed in the court that urged the cessation of her force feeding with a nasogastric tube and the request for her peaceful death. What followed was a string of arguments and counter arguments relating to Euthanasia. The sad demise of Aruna Shanbaug is not the end of an individual, but may be the end of the road for clear cut guidelines and legislation on Euthanasia in India. <http://link.springer.com/article/10.1007/s11948-015-9687-4>

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/publications/newsletter/2015/08/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]

Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://hpcconnection.ca/general-resources/in-the-news/>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to ‘Additional Resources’]

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>

Barry R. Ashpole
Guelph, Ontario CANADA

‘phone: 519.837.8936
e-mail: barryashpole@bell.net