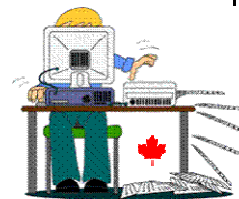


Media Watch...

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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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

Compiled & Annotated by Barry R. Ashpole

Needs of home-care service providers: Scroll down to [Specialist Publications](#) and 'Educational programs for family caregivers in palliative care: A literature review' (p.10), in *Journal of Palliative Care & Medicine*.

Canada

Home-care services still threatened, despite injection of new funding

ONTARIO | *The Windsor Star* – 28 November 2014 – Despite an influx of several million dollars into home-care funding, services in the region will still be reduced. Patients have been on high alert for the past few weeks after the Erie St. Clair Community Care Access Centre [CCAC] revealed it had a massive deficit, which it planned to make up by cutting home nursing visits by 33 per cent and reducing the number of its long-term clients receiving minimal care. That \$5.9-million shortfall – originally reported as \$5 million – was largely eliminated on Thursday when the Local Health Integration Network, which provides the CCAC with funding on behalf of the provincial government, announced new base funding worth \$4.1 million. But reducing nursing visits is still one strategy the CCAC intends to pursue, said CEO Lori Marshall. She confirmed the CCAC still needs to reduce the number of people receiving minimal care by working with other community organizations that might be able to take on new clients. <http://blogs.windsorstar.com/news/home-care-services-still-threatened-despite-injection-of-new-funding>

Noted in Media Watch, 24 November 2014, #385 (p.2):

- ONTARIO | *The Windsor Star* – 20 November 2014 – '**Salaries of top positions at CCAC [Community Care Access Centre] rise despite home care service cuts.**' Over the past five years, the number of salaries higher than \$100,000 at Erie St. Clair CCAC has more than doubled. In 2008, there were 9. In 2013, there were 21. Funded by the Ministry of Health & Long Term Care, Erie St. Clair CCAC is meant to provide and co-ordinate home care for vulnerable sectors of the population – mainly seniors and those who require special medical support. <http://blogs.windsorstar.com/news/salaries-of-top-positions-at-ccac-rise-despite-service-cuts>

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.15.

Palliative care doesn't only go to the dying

BRITISH COLUMBIA | *Georgia Straight* (Vancouver) – 26 November 2014 – Dr. Pippa Hawley is keen to shatter myths about palliative care. The University of British Columbia's medical school's division head of palliative care emphasizes that it's not only for those with terminal illnesses. "The old models of palliative care have not really included survivorship," Hawley explains. "People wait until they're 100% certain that they're going to be dead before they even think of palliative care. But by then they've missed out on so much potential benefit. They then get too little, too late. We want to get people thinking about it earlier and planning ahead." In a three-page letter published last year in the *Journal of Pain & Symptom Management*,¹ Hawley pointed out that the World Health Organization's definition of palliative care has expanded beyond treat-

ing people with incurable diseases. Nowadays, it's applied to life-threatening conditions such as heart disease and renal failure, sometimes early on, to achieve its greatest potential. "Palliative care isn't necessarily a thing or a place," Hawley says. "It's an approach to care, which can be delivered in all sorts of different environments. <https://www.straight.com/life/778556/palliative-care-doesnt-only-go-dying>

Specialist Publications

'Palliative care for the homeless: An intervention to reduce the healthcare economic cost' (p.14), in *Western Undergraduate Research Journal: Health & Natural Sciences*.

1. 'The bow tie model of 21st Century palliative care,' *Journal of Pain & Symptom Management*, 9 December 2013. [http://www.jpmsjournal.com/article/S0885-3924\(13\)00609-X/fulltext](http://www.jpmsjournal.com/article/S0885-3924(13)00609-X/fulltext)

"whole person" care

Reclaiming medicine's spiritual roots: Treating people, not just diseases

THE GLOBE & MAIL | Online – 23 November 2014 – Occupational therapists in Canada have enshrined spiritual care in their guidelines, making it their job to help patients ... tap into life-affirming sources of personal meaning, such as nature or the arts. The new approach to spiritual care is not the same as religious counselling or the healing response associated with the placebo effect. Rather, it is based on the idea that everyone has the need for hope, meaning and purpose in life, and that connecting to one's spirit, the essence of the self, can be a powerful motivator in healing. Researchers in the emerging field of spirituality in medicine argue that science alone cannot meet the needs of aging populations who increasingly suffer from depression, social isolation, and chronic diseases such as diabetes and dementia, which tend to worsen over time. <http://www.theglobeandmail.com/life/health-and-fitness/health/reclaiming-medicines-spiritual-roots-treating-people-not-just-diseases/article21704383/>

Selected articles on spirituality, in the context of end-of-life care, noted in past issues of Media Watch:

- *WESTERN JOURNAL OF NURSING RESEARCH* | Online – 25 May 2014 – **'Describing spirituality at the end of life.'** The authors' analysis of the literature identified five attributes that most commonly described the essence of spirituality: 1) meaning; 2) beliefs; 3) connecting 4) self-transcendence; and, 5) value. [Noted in Media Watch, 2 June 2014, #360 (p.12)] <http://wjn.sagepub.com/content/early/2014/05/23/0193945914535509.abstract>
- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2013;9(2-3). **'Spirituality in end-of-life and palliative care: Theory, research, and practice dimensions for social work.'** The theme of this issue of the journal is "theoretical and practice perspectives in which spirituality plays a key role in end-of-life care." [Noted in Media Watch, 24 June 2013, #311 (p.12)] Journal contents page: <http://www.tandfonline.com/toc/wswe20/current>

Cont.

- *ARCHIVE FOR THE PSYCHOLOGY OF RELIGION*, 2012;34(1):63-81. **'Six understandings of the word "spirituality" in a secular country.'** The authors conclude that a common understanding of the term spirituality does not exist, at least in a modern secular setting. [Findings of this Danish study] resulted in [identifying] six different understandings of spirituality: 1) positive dimensions in human life and well-being; 2) New Age ideology; 3) an integrated part of established religious life; 4) a vague striving, opposed to religion; 5) selfishness; and, 6) ordinary inspiration in human activities. [Noted in Media Watch, 25 June 2012, #259 (p.9)] <http://www.ingentaconnect.com/content/brill/arp/2012/00000034/00000001/art00005>

U.S.A.

Home support for chronically ill cuts costs 44%, Michigan study finds

MICHIGAN | Michigan Live – 25 November 2014 – Providing home care to chronically ill patients cut costs 44% in a ... study conducted by Wayne State University and Hospice of Michigan.¹ Researchers examined the effect of providing medical and daily-care help to patients who have a serious, chronic illness but who do not qualify for hospice care. The patients were enrolled in Hospice of Michigan's At Home Support program. "Patients suffering from chronic illness often find themselves thrust into a 'care gap' that requires them to make difficult choices," said Dr. Michael Paletta, the study co-author and executive director of the Hospice of Michigan Institute. http://www.mlive.com/news/grand-rapids/index.ssf/2014/11/home_support_for_critically_il.html

1. 'Cost analysis of a novel interdisciplinary model for advanced illness management,' *American Journal of Hospice & Palliative Medicine*, 21 February 2014. Study findings suggest @HOME Support is associated with reductions in the use and cost for most health services over time. <http://ajh.sagepub.com/content/early/2014/02/20/1049909114523827.abstract>

Respecting patient's wishes

Getting things right in the face of death

OREGON | *The Oregonian* (Portland) – 24 November 2015 – Dying right can be difficult. The profusion in recent years of living wills and health care proxies has created the popular impression that things will go as stipulated as long as medical personnel read all the paperwork. Sadly, that's only kind of true. The practical reality is that emergency medical technicians correctly see as their task keeping people alive and conveying them to the hospital alive. Because they're good at their jobs, they often do – even when the potential outcome of their success is failure for the terminally ill person who never wanted to end up, say, on mechanical life support systems. Ethicists often use the term slippery slope to describe how quickly choices engulf patients once a course of treatment is chosen or has been chosen for them. Often the choices fall to others. A dis-

cussion no distraught family of a comatose patient ever wishes to undertake is: What do we do now? It's a discussion ... the voiceless would likely not wish upon family members. http://www.oregonlive.com/opinion/index.ssf/2014/11/getting_things_right_in_the_fa.html

Specialist Publications

'Modern dying: From securing rights to meeting needs' (p.8), in *Annals of the New York Academy of Sciences*.

'End-of-life medical costs of Medicaid cancer patients' (p.9), in *Health Services Research*.

'U.S. study examines communication and end-of-life decisions' (p.11), in *Medical Express*.

New Medicaid rule could challenge state shift away from nursing homes

ARKANSAS | *The Times-Record* (Fort Smith) – 23 November 2014 – Starting this year, a new federal rule will require states to ensure that long-term care alternatives to nursing homes – such as assisted living facilities, continuing care retirement communities, group homes, and adult day care – work with residents and their families to develop individual care plans specifying the services and setting each resident wants. The overarching goal is to create a "homelike" atmosphere, rather than an institutional one and to give residents choices about their care. While nearly everyone supports the concept, states, providers and even some consumer advocates are complaining that the rule could make it difficult for health care providers to fulfill increasing demand for long-term care outside of nursing homes. <http://swtimes.com/nationworld/new-medicaid-rule-could-challenge-state-shift-away-nursing-homes>

International

End-of-life care in Australia

Call for more investment in palliative care

AUSTRALIAN AGEING AGENDA | Online – 28 November 2014 – Increased investment in palliative care can result in improved health outcomes for a person at end of life in a cost-effective way, Professor David Currow told the Australian Association of Gerontology national. Professor Currow, who is professor palliative and supportive services at Flinders University, said good end-of-life care aimed to optimise function and comfort in a person's physical, emotional, existential, social, sexual and financial domains. Pain and symptom control is a priority as is supporting the caregivers whom we rely so much on so they know how to provide the best care and where to get help, he said. <http://www.australianageingagenda.com.au/2014/11/28/call-more-investment-palliative-care/>

Elder care in China

Time to rethink care home policy

CHINA (Hong Kong) | *The South China Morning Post* (OpEd) – 25 November 2014 – Auditor's reports seldom lend themselves to compelling headlines. 'Death stalks old as they wait for help' [*sic*] ... is an exception. It was the heading on a report about independent scrutiny by the Audit Commission of the assessment system for people on a three-year waiting list for aged-care places. Sadly the heading was not unjustified. The commission found that 5,700 people died last year while waiting to enter care homes, compared with an average of 4,000 to 4,500 deaths a year before 2010. It also expressed concern about a couple of other administrative issues affecting an ageing society's most vulnerable members. <http://www.scmp.com/comment/insight-opinion/article/1647917/time-rethink-care-home-policy>

Specialist Publications

'Motivations of German hospice volunteers: How do they compare to non-hospice volunteers and U.S. hospice volunteers?' (p.8), in *American Journal of Hospice & Palliative Medicine*.

'End-of-life care and Māori whānau resilience' (p.11), in *Mai Journal*.

Media Watch posted on Palliative Care Network-e Website

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

Cont.

Noted in Media Watch, 24 November 2014, #385 (p6):

- CHINA (Hong Kong) | *The South China Morning Post* – 20 November 2014 – '**Number of elderly dying in Hong Kong while awaiting care home places soars.**' The number of elderly people who die while waiting for places in care homes has shot up in the past four years, the Audit Commission has revealed in a damning report. <http://www.scmp.com/news/hong-kong/article/1644463/5700-hong-kong-elderly-died-awaiting-place-care-home-last-year-1200>

End-of-life care in Ireland

People with terminal illnesses no longer face medical card review

IRELAND | *The Irish Times* (Dublin) – 25 November 2014 – People with terminal illnesses will no longer have to have their medical card reviewed, Minister for Health has announced as part of a major change to the system. Changes in the medical card system will see more account taken of the burden of an illness as part of an "enhanced" assessment process. The power of a GP to extend a medical card in difficult circumstances is to be extended to four months and to 12 months in sensitive cases. More than 10,000 people, who had their medical cards removed and later reinstated, have been told they will retain the cards pending implementation of actions to improve the scheme. <https://www.irishtimes.com/news/health/people-with-terminal-illnesses-no-longer-face-medical-card-review-1.2014507>

Noted in Media Watch, 13 October 2014, #379 (p.8):

- IRELAND | *The Irish Times* (Dublin) – 4 October 2014 – '**Medical cards and GP visit cards cover 43% of population.**' Despite its name, a "medical card" is generally allocated on financial grounds rather than on grounds of illness. Almost two million people, or 43% of the population, are covered by either a medical card or a GP visit card. The number of cards has increased by 74% since 2005, a result of increasing unemployment and an ageing population. <http://www.irishtimes.com/news/health/medical-cards-and-gp-visit-cards-cover-43-of-population-1.1951700>

Friendly young doctors lack objectivity and are bad for your health, study finds

AUSTRALIA | *The Australian* – 24 November 2014 – Two-thirds of young doctors say they struggle to be objective and truthful with patients they like, according to researchers who warn that "chummy" medics are blurring the boundaries between personal and professional relationships.¹ Doctors should not allow patients to call them by their first name, accept them as friends on Facebook or greet them with a hug, because this could impair their clinical judgment. Doctors are rightly encouraged to be empathetic with patients, but a sympathetic look or a pat on the arm are enough and doctors should not feel the need "to do the sort of thing you would do if it was your mum or your best friend." Survey of 338 oncologists under the age of 40 revealed 59% said that they found it difficult to be truthful if they liked a patient, and 60% felt if doctors were too empathetic

they could not make objective decisions. <http://www.theaustralian.com.au/news/world/friendly-young-doctors-lack-objectivity-and-are-bad-for-your-health-study-finds/story-fnb64oi6-1227132807495?nk=1fbe7436605bd2a26f9b543de75c9700>

Quote from *The Australian* article

"You don't want your doctor to start censoring themselves because they don't want to upset you. For example, if instead of having a painful conversation about palliative care, you recommend more (fruitless) chemotherapy with all its side effects, you really haven't done well by your patients."

1. 'Blurring of boundaries in the doctor – patient relationship,' *The Lancet Oncology*, 2014;15(13): 1423-1424. [http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(14\)71122-2/fulltext](http://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(14)71122-2/fulltext)

End-of-life care in South Africa

Dwindling donations threaten hospices

SOUTH AFRICA | *Business Day* (Johannesburg) – 24 November 2014 – Hospice and palliative care centres have less than half of the 1 billion Rand [equal to approximately \$91 million U.S.] they need to function annually and "a fair percentage" of their 4,300 staff members are facing re-trenchment. Funding has dried up from sources such as the National Lottery Distribution Trust Fund and corporate South Africa, which blame tough economic times for dwindling donations. <http://www.bdlive.co.za/national/health/2014/11/24/dwindling-donations-threaten-hospices>

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

Patients leave end-of-life care choice to medics, survey finds

U.K. (England, Northern Ireland, Scotland & Wales) | *The Independent* (London) – 23 November 2014 – Major decisions about how people are cared for at the end of their lives are being left to doctors – despite fewer than one in 10 patients wanting this to happen. Only 7% of adults in Britain want a doctor to have the final say on their end-of-life care, according to [recent] research...¹ Despite this, only four percent have either made a record of their preferences in an Advance Decision or appointed a Lasting Power of Attorney. The research ... suggests that the remaining 91% have by default left these serious decisions to doctors, who may prolong their life against a person's wishes. The Government should prioritise the issue of a "good death" and do more to make patients aware of their right to record their views on end-of-life care. The findings come

amid mounting evidence of a gulf between patients' wishes and the reality of dying in the U.K. The Royal College of Physicians found that in a recent audit patients were not being fully informed about their end-of-life situation.² <http://www.independent.co.uk/life-style/health-and-families/health-news/patients-leave-endoflife-care-choice-to-medics-survey-finds-9877878.html>

Extract from *The Independent* report

A Health Department spokesperson said: "We have commissioned an independently led review to provide advice on delivering greater choice and quality in end of life care." The review is expected to report early next year.

1. 'Who do you want to make decisions for you at end of life – YouGov Poll (2014),' Compassion in Dying. <http://www.compassionindying.org.uk/decisions-end-of-life-yougov-poll>
2. 'National Care of the Dying Audit of Hospitals,' Royal College of Physicians in collaboration with the Marie Curie Palliative Care Institute Liverpool, 14 May 2014. [Noted in Media Watch, 19 May 2014, #358 (p.3)] <http://www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals>

Of related interest:

- U.K. (England) | *The Gloucestershire Echo* (Cheltenham) – 28 November 2014 – **""Right to die" ruling will allow Gloucestershire man in permanent vegetative state to die with dignity.** The "right-to-die" ruling was given in London by [High Court judge] Mr. Justice Baker. He held that Gloucestershire Clinical Commissioning Group (CCG) should be allowed to withdraw artificial hydration and nutrition from the 55-year-old man and allow him to die with dignity. <http://www.gloucestershireecho.co.uk/Right-die-ruling-allow-Gloucestershire-man/story-24836036-detail/story.html>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Telegraph* – 27 November 2014 – '**Growing number of doctors support assisted dying.**' One in three doctors supports assisted dying and a growing number would help their own patients to die, a survey of 8,000 medics has found. The poll by the Royal College of Physicians comes as the Lords debates a bill which would allow terminally ill patients with less than six months to live end their lives with a fatal dose of medicine. The Royal College said it would retain its stance opposing such changes – but said the findings signalled a "shift in opinion" among the medical community. In total, 32.3% said they supported a change in the law to permit assisted suicide by the terminally ill with the assistance of doctors. <http://www.telegraph.co.uk/news/politics/11259136/Growing-number-of-doctors-support-assisted-dying.html>
- AUSTRALIA (Victoria) | ABC News (Melbourne) – 23 November 2014 – '**Victorian election 2014: Electorate overwhelmingly back voluntary euthanasia...**' Victorians overwhelmingly support voluntary euthanasia for terminally ill patients, putting them at odds with the Coalition and Labor parties on the issue, according to Vote Compass results. On the question, "Terminally ill patients should be able to legally end their own lives with medical assistance," more than three quarters of survey respondents supported medically assisted suicide. The Coalition strongly disagrees with medically assisted suicide, yet 71% of coalition voters want to legalise voluntary euthanasia. The Labor Party somewhat disagrees with the assisted suicide, while 79% of ... supporters are in favour. The Greens strongly support voluntary euthanasia and a large majority of its voters support that stance. <http://www.abc.net.au/news/2014-11-23/victorians-back-voluntary-euthanasia-vote-compass/5910668>

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

Family members' experience with hospice in nursing homes

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 25 November 2014
Research has documented numerous benefits and challenges associated with receipt of hospice care in nursing homes; however, study of this partnership from the perspective of residents' family members has been limited. Findings [of this study] highlighted the critical role of communication in supporting residents and their family members. Care coordination, support and oversight, and role confusion also impacted family members' experience of hospice care in the nursing home. <http://ajh.sagepub.com/content/early/2014/11/24/1049909114560213.abstract>

Noted in Media Watch, 17 November 2014, #384 (p.6):

- *JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION*, 2014;15(10):744-750. '**Hospice family members' perceptions of and experiences with end-of-life care in the nursing home.**' The family members of nursing home residents reported higher quality of life; however, levels of anxiety, depression, perceptions of pain medicine, and health were similar for hospice family members in the nursing home and in the community. Some family members reported positive end-of-life care experiences in the nursing home setting. [http://www.iamda.com/article/S1525-8610\(14\)00340-5/abstract](http://www.iamda.com/article/S1525-8610(14)00340-5/abstract)
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 November 2014 – '**Prevalence and description of palliative care in U.S. nursing homes: A descriptive study.**' There is limited availability of palliative type programs in nursing homes and underutilization in those with programs. Hospice is significantly more available than palliative or comfort care programs... <http://ajh.sagepub.com/content/early/2014/11/12/1049909114558585.abstract>

N.B. In the U.S., hospice care and palliative care are similar when it comes to the most important issue for dying people: care. Where they differ is in the location of care, timing, method of payment and eligibility for services. (Source: National Caregivers Library. <http://www.caregiverslibrary.org/caregivers-resources/grp-end-of-life-issues/hsgrp-hospice/hospice-vs-palliative-care-article.aspx>)

Motivations of German hospice volunteers: How do they compare to non-hospice volunteers and U.S. hospice volunteers?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 23 November 2014 – The U.S. hospice volunteers reported motives related to altruistic concerns, enhancement, and social influence as more influential, while German hospice volunteers rated career expectations as being more important. Comparison of German hospice with non-hospice volunteers revealed stronger differences: German hospice volunteers scored higher on altruistic motives, while German non-hospice volunteers yielded higher scores on self-serving motives. Findings contribute to improved understanding of volunteering motivation and of activating or retaining hospice volunteers. <http://ajh.sagepub.com/content/early/2014/11/24/1049909114559067.abstract>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 25 November 2014 – '**Motivations, satisfaction, and fears of death and dying in residential hospice volunteers: A Prospective longitudinal study.**' Motivations to volunteer [among survey respondents] remained stable over time while volunteer satisfaction increased with time. Volunteering in a residential hospice tends to be a satisfying experience that helps to allay fears about death and dying. <http://ajh.sagepub.com/content/early/2014/11/24/1049909114559830.abstract>

N.B. Additional articles on the motivations of hospice volunteers are noted in Media Watch, 10 November 2014, #383 (pp.10-11).

Modern dying: From securing rights to meeting needs

ANNALS OF THE NEW YORK ACADEMY OF SCIENCES, 2014;1330:105-110. The U.S. healthcare system is not designed to meet the needs of people with chronic illness or of frail elders. The system incentivizes the use of technologies that are often helpful when an underlying condition is reversible but, when used very near the end of life, may only postpone the dying process and increase burdens on the patient. This state of affairs renders many people near the end of life without adequate symptom control, little or no social and psychological support, and inadequate involvement in decisions about when and how best to use modern technologies. This paper traces efforts over the last three decades to address problems related to modern dying. The author sees three phases: early work focused on securing patients' rights to refuse unwanted treatments, the next phase focused on building the specialty of palliative medicine, and the third and future phase must redesign the healthcare system to better align with how we die in the 21st century. <http://onlinelibrary.wiley.com/doi/10.1111/nyas.12581/abstract;jsessionid=1BA921D62243C4C2472E0360DFCFB0CA.f04t02?deniedAccessCustomisedMes-sage=&userIsAuthenticated=false>

Eleanor Roosevelt's last days: A bioethical case study

AMERICAN JOURNAL OF MEDICINE | Online – 24 November 2014 – When Eleanor Roosevelt died in 1962, she was widely regarded as "the greatest woman in the world." In spite of her celebrity, or more likely because of it, she was forced to endure a protracted period of intense suffering and humiliation before dying. On critical analysis, her end-of-life care violated most of the ethical standards of care for the dying we hold dear today. However, caring for dying celebrities continues to be especially difficult. In at least some instances, the terminal care given to recently deceased world leaders has been no more consistent with these standards than that given to Eleanor Roosevelt over 50 years ago. [http://www.amjmed.com/article/S0002-9343\(14\)01079-1/abstract](http://www.amjmed.com/article/S0002-9343(14)01079-1/abstract)

N.B. This issue of the *Annals of the New York Academy of Sciences* explores "the boundaries between life and death." Journal contents page: <http://onlinelibrary.wiley.com/doi/10.1111/nyas.2014.1330.issue-1/issuetoc>

Cont.

Of related interest:

- *SCIENTIFIC AMERICAN* | Online – 26 November 2014 – **'The emergence of death and dying as we know it.'** While people may certainly mourn or hold memorials in their homes, more often than not, people go to where the body is to pay their final respects, which means mourning occurs in the designated spaces of funeral homes. There are professionals who oversee the rituals associated with saying goodbye ... charged with the care and maintenance of the deceased's body until the rites are over. Death is a thriving industry; it has been institutionalized. <http://blogs.scientificamerican.com/anthropology-in-practice/2014/11/26/the-emergence-of-death-and-dying-as-we-know-it/>

Medical futility: Is a policy needed?

CLINICAL RESEARCH & BIOETHICS | Online – 31 October 2014 – Medical futility generally refers to the inappropriate application of medical intervention that is unlikely to produce any significant benefit for the patient. Medical futility, once called "a problem without a name," remains a controversial issue in its definition as well as in its applications. The controversy exists, partly, in disagreements between families and physicians about the patient's best interests, the goals of treatment and the ends of medicine. In everyday clinical practice, physicians are under pressure to make decisions whether or not to offer futile treatment and how to communicate their decisions with the family. However, in some cases there are disagreements between healthcare providers and patients' family about the course of action. The inevitability of human death, limitations of medical science, the scarcity of health resources, and various socio-cultural issues shape decisions regarding end-of-life care in general and medical futility in particular. In an era with an aging population and escalating healthcare costs, the futility debate has become the object of extended critical attention. Currently, except in some hospitals in the U.S., there is a lack of policy or regulation in dealing with medical futility. It is crucial to develop futility policies which guide healthcare professionals on the process for decision making on the treatment options, and when it is morally permissible to withhold or withdraw life-sustaining treatment. Such policies would be very instrumental in decreasing disagreement. <http://omicsonline.org/open-access/medical-futility-is-a-policy-needed-2155-9627.1000e102.pdf>

End-of-life medical costs of Medicaid cancer patients

HEALTH SERVICES RESEARCH | Online – 25 November 2014 – End-of-life costs during the final four months of life [of the Medicaid beneficiaries included in this study] were about \$10,000 higher for Medicaid cancer patients than for those without cancer. They are more intensive users of inpatient and ambulatory services than are Medicaid patients without cancer. This increased cost may reflect the cost of palliative care. <http://onlinelibrary.wiley.com/doi/10.1111/1475-6773.12259/abstract;jsessionid=654F3AC1DD8974896FD6381E3ABF4374.f01t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

"That would have been beneficial": Lesbian, gay, bisexual, transgender and queer education for home-care service providers

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 27 November 2014 – This paper reports findings from a study that explored the lesbian, gay, bisexual, transgender and queer (LGBTQ) education needs of home-care service providers working in one large, urban Canadian city. LGBTQ activists, organisations and allies have underscored the need for health provider education related to the unique health and service experiences of sexual and gender minority communities. The home-care sector is generally overlooked in this important body of research literature. This study findings raise important questions about limited and uneven access to adequate LGBTQ education for home-care service providers, suggest important policy implications for the education and health sectors, and point to the need for anti-oppression principles in the development of education initiatives. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12141/abstract>

Cont.

Of related interest:

- *JOURNAL OF PALLIATIVE CARE & MEDICINE* | Online – 8 November 2014 – '**Educational programs for family caregivers in palliative care: A literature review.**' This review testifies the lack of publications regarding programs designed and developed to support family caregivers in PC. It is shown that caregivers benefit from support groups and educational programs to promote information and caregiver training, but perhaps the lack of funding for this kind of interventions can affect the caregiver's treatment. <http://omicsgroup.org/journals/educational-programs-for-family-caregivers-in-palliative-care-a-literature-review-2165-7386.1000195.pdf>
- *SUPPORTIVE CARE IN CANCER* | Online – 29 November 2014 – '**The interaction between informal cancer caregivers and health care professionals: A survey of caregivers' experiences of problems and unmet needs.**' A total of 590 caregivers (related to 415 (55 %) of 752 eligible patients) participated. Although many caregivers were satisfied, considerable proportions experienced problems or had unmet needs regarding the interaction with health care professionals (HCPs). Prominent problematic aspects included optimal involvement of the caregivers in the patients' disease, treatment and/or care (30 % were dissatisfied), attention to the caregivers' wellbeing (e.g., 51 % of the caregivers reported that HCPs only sometimes or rarely/never had shown interest in how the caregivers had been feeling), and provision of enough information to the caregivers (e.g., 39 % were dissatisfied with the amount of time spent on informing caregivers). <http://link.springer.com/article/10.1007/s00520-014-2529-0>

Noted in Media Watch, 17 November 2014, #384 (p.8):

- *LA CLINICA TERAPEUTICA*, 2014;165(5):e357-e361. '**Family caregiver education: An Italian experience.**' The reliance on family caregivers unprepared for the daily management of the patient's illness may threaten the patients' quality of life and, moreover, increase the burden of care on the caregiver by exposing them to the risk of psychosocial distress. http://www.seu-roma.it/clinica_terapeutica/apps/autos.php?id=1373

Relationship with God, loneliness, anger, and symptom distress in patients with cancer who are near the end of life

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2014;16(8):482-488. The study purpose was to explore relationship with God, symptom distress, and feelings of anger and loneliness in hospice patients with cancer. Three hundred fifty-four hospice patients completed the Memorial Symptom Assessment Scale & Hospice Quality of Life Index. If patients felt that they did not have a good relationship with God, they were more likely to feel anger. Patients who had a better relationship with God felt less lonely, which might suggest that religion was more than a set of beliefs but was a source of comfort, care, and support. Patients who perceived a satisfactory relationship with God reported less symptom distress. Patients appeared to be able to maintain their relationships with God. However, they still had other problems such as anger, loneliness, and symptom distress that are associated with their God relationship and that deserve attention. Thus, the interdisciplinary team, which includes chaplains, is critical and should remain the standard. http://journals.lww.com/jhpn/Abstract/2014/12000/Relationship_With_God,_Loneliness,_Anger,_and.9.aspx

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Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

Noted in Media Watch, 24 January 2011, #185 (p.10):

- *PALLIATIVE MEDICINE*, 2011;25(1):21-25. 'Hope beyond (redundant) hope: How chaplains work with dying patients.' The author identifies four organic moments in the chaplain-patient relationship, each moment being a discernible development in the chaplain's being-with the patient: "evocative presence," "accompanying presence," "comforting presence" and "hopeful presence." <http://pmj.sagepub.com/content/25/1/21.abstract>

End-of-life care and Māori whānau resilience

MAI JOURNAL, 2014;3(2):140-152. This article focuses on the cultural resources that made Māori carers resilient when providing care to an ill family member at the end of life. Caring often took place against a backdrop of poverty, personal factors, racism and a lack of health literacy affecting access to resources. The action values of aroha [love, care, concern, compassion] and manaakitanga [hospitality, kindness, generosity], compassionate giving, caring, receiving and sharing established a resilient foundation upon which whānau [family, including extended family] engaged in the illness-to-death trajectory. It served to fortify the dying and their whānau and provided a sense of belonging and a meaningful way of engaging with illness, dying, death and bereavement. http://www.journal.mai.ac.nz/sites/default/files/MAI_Jrnl_V3_iss2_Maxwell.pdf

N.B. Additional articles on Māori beliefs and practices in the context of end-of-life care are noted in Media Watch, 16 June 2014, #362 (p.8) and 17 March 2014, #349 (p.9).

U.S. study examines communication and end-of-life decisions

MEDICAL EXPRESS | Online – 24 November 2014 – Allison Scott, at the College of Communication & Information, University of Kentucky, focuses her research on the quality of communication about end-of-life health decisions. In her [recent] study¹ ... Scott, and co-author John Caughlin ... at the University of Illinois at Urbana-Champaign, used a multiple goals theoretical perspective to demonstrate the quality of communication about end-of-life decisions matters. "The way an end-of-life discussion is negotiated has the potential to strengthen or undermine relationships," says Scott. "Family communication holds a great deal of potential for im-

proving end-of-life health care, but this potential lies in the quality of the discussions." <http://medicalxpress.com/news/2014-11-uk-end-of-life-decisions.html>

Extract from *Medical Express* article

People who paid better attention to task, identity and relational goals were more satisfied with the conversation, felt [after the conversation] more hopeful, experienced less hurt, and felt less relationally distanced.

1. 'Enacted goal attention in family conversations about end-of-life health decisions,' *Communication Monographs*, 2014;81(3):261-284. Most research on end-of-life communication has been based on the assumption more communication is better communication. The authors used a multiple goals theoretical perspective to demonstrate that the quality of communication matters. <http://www.tandfonline.com/doi/full/10.1080/03637751.2014.925568>

Palliative and end-of-life care in pediatric solid organ transplantation

PEDIATRIC TRANSPLANTATION | Online – 25 November 2014 – Transplant teams do not always make timely referrals to palliative care teams due to various clinician and perceived family barriers, an important one being the simultaneous, active care plan each patient would have alongside an end-of-life plan. <http://onlinelibrary.wiley.com/doi/10.1111/petr.12387/abstract>

Cont.

Noted in Media Watch, 27 January 2014, #342 (p.10):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(1):30-33. **'More palliative care involvement is needed for transplant patients.'** Patients who have already received a transplant, as well as those who are on a waiting list for an organ transplant, have large unmet needs for high-quality palliative and end-of-life care.

N.B. Access to the *European Journal of Palliative Care* requires a subscription:
<http://www.haywardpublishing.co.uk/ejpc.aspx>

Palliative care among heart failure patients in primary care: A comparison to cancer patients using English family practice data

PLOS ONE | Online – 25 November 2014 – Patients with heart failure have a significant symptom burden and other palliative care needs often over a longer period than patients with cancer. Among patients with heart failure [in the first use of Clinical Practice Research Datalink, the world's largest primary care database to explore recognition of the need for palliative care] 7% ... were entered on the palliative care register compared to 48% ... of cancer patients. Of heart failure patients on the palliative care register, 29% ... were entered onto the register within a week of their death. This confirms that the stark inequity in recognition of palliative care needs for people with heart failure in a large primary care dataset. The authors recommend a move away from prognosis based criteria for palliative care towards a patient centred approach, with assessment of and attention to palliative needs including advance care planning throughout the disease trajectory. <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0113188>

Selected articles on the lack of referral of heart failure patients to palliative care noted in past issues of Media Watch:

- *JOURNAL OF PALLIATIVE MEDICINE*, 2014;17(7):753-760. **'Engaging heart failure clinicians to increase palliative care referrals: Overcoming barriers, improving techniques.'** Better models to integrate palliative care earlier in the disease trajectory and a stronger evidence base for the role of palliative care for these patients are desperately needed. Because the course of heart failure is complex and unpredictable, the focus of palliative care offered must fit this different paradigm. [Noted in Media Watch, 14 July 2014, #366 (p.11)] <http://online.liebertpub.com/doi/full/10.1089/jpm.2013.0675>
- *JOURNAL OF THE AMERICAN HEART ASSOCIATION* | Online – 2 January 2014 – **'Not the "grim reaper service": An assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure.'** Providers [i.e., study participants] had limited knowledge regarding what palliative care is and how it can complement traditional HF [heart failure] therapy to decrease HF-related suffering. [Noted in Media Watch, 13 January 2014, #340 (p.11)] <http://jaha.ahajournals.org/content/3/1/e000544.full.pdf+html>

Psychiatry's place in caring for the terminally ill

PSYCHIATRY TIMES | Online – 25 November 2014 – The Institute of Medicine recently released its report [on end-of-life care in the U.S.] and its general thrust is that we have a long way to go in providing appropriate care for those nearing the end of their lives.¹ There are several portions of special importance to psychiatrists, especially the discussion of the role psychiatrists could and ... should be playing regarding end-of-life decisions as well as, not coincidentally, pain management. <http://www.psychiatrytimes.com/cultural-psychiatry/psychiatrys-place-caring-terminally-ill>

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine, September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/~media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf>

Cont.

Of related interest:

- *ACADEMIC PSYCHIATRY* | Online – 27 November 2014 – '**Palliative care training for psychiatry residents: Development of a pilot curriculum.**' Palliative care incorporates mental health issues such as grief, depression, delirium, anxiety, sleep disruption, family conflict, and treatment decision-making. Conversely, psychiatry emphasizes communication with patients and providing empathy and other elements of palliative care near the end of life. Thus, there is opportunity for each to enhance the other. <http://link.springer.com/article/10.1007/s40596-014-0244-2>

Noted in Media Watch, 3 March 2014, #347 (p.9):

- *INTERNATIONAL REVIEW OF PSYCHIATRY*, 2014;26(1):87-101. '**A comprehensive review of palliative care in patients with cancer.**' Patients with advanced cancer, and other life-threatening medical illnesses are at increased risk for developing major psychiatric complications and have an enormous burden of both physical as well as psychological symptoms. <http://informahealthcare.com/doi/abs/10.3109/09540261.2013.868788>

Noted in Media Watch, 14 October 2013, #327 (p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 4 October 2013 – '**Current state of psychiatric involvement on palliative care consult services: Results of a [U.S.] national survey.**' There are shared objectives between psychiatry and palliative care; however, co-involvement on treatment teams is limited. Research is needed to identify ways to facilitate the interface of palliative care and psychiatry. [http://www.jpsmjournal.com/article/S0885-3924\(13\)00401-6/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00401-6/abstract)

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

End-of-life care for the homeless in Canada

An intervention to reduce the healthcare economic cost

WESTERN UNDERGRADUATE RESEARCH JOURNAL: HEALTH & NATURAL SCIENCES, 2014;5(1):1-3. Canada's health care system is one of the defining features of the country. For the past few years – since the economic downturn of 2008 – the health care system has been strained. Furthermore, with Canada's population aging at a fast rate, and older adults being the population that uses the most health care resources, it is imperative to find ways that decrease expenditures while continuing to provide effective care. Through implementing palliative care for Canada's homeless population, resources will be used more effectively and efficiently. In the Ottawa Inner City Health Project – The Hospice – \$1.39 million were saved for a mere 28 clients who used the hospice services over an average of 120 days. Providing homeless people palliative care helps to solve this problem and provides services to people who are marginalized and often unable to access care – it shows the humanity that people associate with Canada. <http://ir.lib.uwo.ca/cgi/viewcontent.cgi?article=1068&context=wurjhns>

Noted in Media Watch, 11 August 2014, #370 (p.2):

- CANADA (Ontario) | CTV News – 3 August 2014 – **'Mobile palliative programs give "end-of-life-care" to homeless.'** They're too often the forgotten people – or the ones many of us turn a blind eye to as we pass a street corner where they might implore us for extra change: the homeless living rough outside through all kinds of weather or those precariously housed in a cot-for-the-night shelter or a decaying rooming house. But what happens when these people are dying? Where do they find care in their final days? <http://www.ctvnews.ca/canada/mobile-palliative-programs-give-end-of-life-care-to-homeless-1.1944757>

Noted in Media Watch, 15 November 2010, #175 (p.7):

- CANADA (Nova Scotia) | Canadian Healthcare Network – 9 November 2010 – **'End-of-life care for homeless.'** For homeless and marginalized people on the streets of Halifax, Nova Scotia, there's a good chance that, when their time comes, they may not have the opportunity to choose the kind of end-of-life care that they would prefer. Monica Flinn, RN, is part of a group that is working to change that ... with the Mobile Outreach Street Health Program... <http://www.canadianhealthcarenetwork.ca/nurses/news/movers-shakers/monica-flinn-end-of-life-care-for-homeless-6956>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *ANNALS OF THE NEW YORK ACADEMY OF SCIENCES*, 2014;1330:94-100. **'Oregon's experience with aid in dying: Findings from the death with dignity laboratory.'** This article provides a summary of data highlights, gleaned from scientific investigations and governmental reporting. <http://onlinelibrary.wiley.com/doi/10.1111/nyas.12486/abstract>
- *BIOETHICS* | Online – 25 November 2014 – **'Why not commercial assistance for suicide? On the question of argumentative coherence of endorsing assisted suicide.'** The article questions if this position – endorsement of physician-assisted suicide on the one hand and rejection of commercially assisted suicide on the other hand – is a coherent ethical position. To this end the article first discusses some obvious advantages of commercially assisted suicide and then scrutinizes six types of argument about whether they can justify the rejection of commercially assisted suicide while simultaneously endorsing physician-assisted suicide. The conclusion is that they cannot provide this justification and that the mentioned position is not coherent. People who endorse physician-assisted suicide have to endorse commercially assisted suicide as well, or they have to revise their endorsement of physician-assisted suicide. <http://onlinelibrary.wiley.com/doi/10.1111/bioe.12140/abstract>

Cont.

- *BMC PALLIATIVE CARE* | Online – 27 November 2014 – '**Death wishes and explicit requests for euthanasia in a palliative care hospital...**' The authors' data show the existence of various expressions of WD [wishes to die] with a low incidence of ER [euthanasia requests] in a French palliative care hospital. The observation of WD including ER is suggestive of good communication between the patients and the care teams. Independent of the changeability of expressions of WD, their very existence should lead to a consideration of the dynamic changes in these WD, and to care staff paying additional attention to the individual, their suffering and the context. <http://www.biomedcentral.com/content/pdf/1472-684X-13-53.pdf>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/10/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

ALBERTA HOSPICE PALLIATIVE CARE ASSOCIATION: <http://ahpca.ca/> (Scroll down to 'Media Watch')

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

ONTARIO | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1>

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>

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