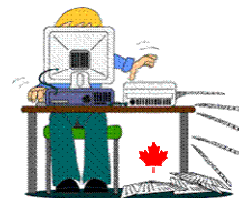


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Patient best interests and prognostic accuracy: Scroll down to [Specialist Publications](#) and 'Uncertainty in end-of-life care' (p.9), in *Current Opinion in Critical Care*.

Canada

At-home care failing seniors: Report

BRITISH COLUMBIA | *The Daily News* (Kamloops) – 15 November 2013 – A large segment of Kamloops senior citizens is falling through the cracks when it comes to at-home care, says a local seniors advocacy group. The situation is showing little improvement despite an elaborate investigation into residential care by the B.C. Ombudsman office.¹ That's because the Health Ministry ignored most of the recommendations in the February 2012 ombudsman report on seniors' care, said a think tank calling for government action for an aging population this week. The Canadian Centre for Policy Alternatives said the government has failed to act on 140 of the 176 recommendations made by ombudswoman Kim Carter.² <http://www.kamloopsnews.ca/article/20131115/KAMLOOPS0101/131119936/-1/kamloops01/at-home-care-failing-seniors-report>

Extract from Ombudsperson report

More privacy and flexibility with daily routines are needed in the provision of appropriate end-of-life care. Counselling services, pain and symptom management and compassionate nursing care should be planned and coordinated in a way that respects the dignity and choices of seniors who are nearing death.

Extract from The Canadian Centre for Policy Alternatives report

The Ombudsperson's recommendations represent "an historic opportunity to strengthen the services and supports that can help BC's growing population of seniors to age in place and to die with dignity."

1. 'The Best of Care: Getting it Right for Seniors in British Columbia,' Office of the Provincial Ombudsman, February 2012. [Noted in Media Watch, 20 February 2012, #241 (p.2): http://www.ombudsman.bc.ca/images/pdf/seniors/Seniors_Report_Volume_2.pdf
2. 'The Ombudsperson's Report on Seniors Care A Brief Analysis of the Government's (Non)Response,' The Canadian Centre for Policy Alternatives, November 2013. http://www.policyalternatives.ca/sites/default/files/uploads/publications/BC%20Office/2013/11/CCPA-BC_Ombudsperson_Seniors_Care.pdf

Specialist Publications

'Defining and measuring a palliative approach in primary care' (p.9), in *Canadian Family Physician*.

'Meaning-making and managing difficult feelings: Providing front-line end-of-life care [in one Canadian city]' (p.9), in *OMEGA – Journal of Death & Dying*.

'Identification of spiritual and religious needs of terminally ill patients receiving palliative home-care [in Quebec]' (p.11), in *Journal for the Study of Spirituality*.

U.S.A.

An oncologist's sense of abandonment

When the doctor disappears

THE NEW YORK TIMES | Online – 14 November 2013 – Dr. Daniel Geynisman felt as if he had abandoned his patient, a sickening sensation. A 65-year-old man with metastasized gall bladder cancer had developed intractable pain before the doctor went away on vacation. By the time Dr. Geynisman returned, the patient was enrolled in hospice; he died soon thereafter. The oncologist never saw him again. The sudden termination of a close doctor-patient relationship is a common, wrenching scenario. "I can tell you, it happens all the time and it breaks the heart of patients and families and oncologists," said Dr. Diane Meier, director of the Center to Advance Palliative Care at Mount Sinai's Icahn School of Medicine in New York City. In an article published in the *Journal of Clinical Oncology*, Dr. Geynisman described his own experience with this sort of estrangement.^{1,2} http://newoldage.blogs.nytimes.com/2013/11/14/when-the-doctor-disappears/?_r=0

1. 'Doctor, where art thou?' *Journal of Clinical Oncology*, 2013;31(12):1606-1608. <http://jco.ascopubs.org/content/31/12/1606.full>
2. 'Hospice and where the doctor can be,' *Journal of Clinical Oncology*, 2013;31(29):3723. Response (in part) to Dr. Geynisman's article: "We do not know the detailed circumstances of Geynisman's patients that led to his inability to participate in their care when they entered hospice, but we do wish to remind our hematology and oncology colleagues that when they refer their patients for hospice care, they need not abandon them. Medicare does allow the hospice attending of record to bill Medicare ... for professional services that are provided to the patient." <http://jco.ascopubs.org/content/31/29/3723.1.full?sid=dad4b23f-cfff-489c-bcc0-59eab2df7c97>



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>

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.18.

Dartmouth Atlas Project

7 tips for receiving better cancer care near the end of life

PUBLIC BROADCASTING SYSTEM | Online – 12 November 2013 – Looking for the best care possible for you or a loved one facing advanced cancer? First step: consider your location. A review of Medicare patients by the Dartmouth Atlas Project revealed some glaring discrepancies in care throughout the nation.¹ In Manhattan in 2010, 43% of Medicare patients with advanced cancer died in a hospital, compared with just 12.2% in Sarasota, Florida. In McAllen, Texas, more than half of Medicare patients with cancer spent time in an intensive care unit in their last month of life, compared with 10.7% in Appleton, Wisconsin. And patients with advanced cancer in Bend, Oregon, were three times as likely to receive hospice care than those in the Bronx [New York City] (26.7%). These wide variations should be cause for alarm nationwide, according to the authors of the Dartmouth Atlas report. They believe that the numbers run counter to "most patients with cancer who are ap-

proaching the end of their lives prefer supportive care that minimizes symptoms and their days in the hospital." But, they conclude "unfortunately, the care patients receive does not always reflect their own preferences but the prevailing styles of treatment in the regions and health care systems where they happen to receive treatment." <http://www.pbs.org/newshour/runtdown/2013/11/7-ways-to-get-better-cancer-care.html>

Specialist Publications

'Comparison of hospice use by European Americans, African Americans, and Latinos: A follow-up study' (p.8), in *American Journal of Hospice & Palliative Medicine*.

'The use of innovative advance directives programs in nursing homes' (p.14), in *The Health Care Manager*.

1. 'Tracking Improvement in the Care of Chronically Ill Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life,' The Dartmouth Institute, 12 June 2013. [Noted in Media Watch, 17 June 2013, #310 (p.4)] http://www.dartmouthatlas.org/downloads/reports/EOL_brief_061213.pdf

"It's about Life" – Changing Korean American's view of palliative care

CALIFORNIA | *New America Media* (Sacramento) – 11 November 2013 – Eunice Kim has spent the past three years working as medical interpreter in San Francisco, where she helps Korean patients communicate with their doctors. More than once she's found herself involved in discussions around key medical decisions for her clients. And no discussion is more difficult ... than when it concerns end-of-life care. "Most of the patients I've worked with have tended not to make decisions for themselves," said Kim. That's partly to do with language barriers. Many of Kim's clients are seniors with limited English skills. But it's also tied to a general reluctance to speak directly of one's own or a relative's mortality. <http://newamericamedia.org/2013/11/its-about-life---changing-korean-americans-view-of-palliative-care.php>

American Public Health Association seeks to improve and rebrand public health

GOVERNMENT HEALTH IT | Online – 11 November 2013 – The American Public Health Association [APHA] is envisioning public health models of palliative care that incorporate patient-centered medical home design, investments in the palliative care workforce, and public education campaigns explaining patient rights in pain management and end-of-life care. Considering the growing burden of life-limiting and chronic disease among older adults, APHA calls for public health-based prevention strategies to improve overall population and gerontological health. It also calls for increasing access to palliative care, supporting development of the palliative care workforce, conducting public education on the right to palliative care and pain management, and funding for additional research. <http://www.govhealthit.com/news/improving-and-rebranding-public-health>

International

End-of-life care in Australia

Too much medicine wasted on the dying, end-of-life care report says

AUSTRALIA | *The Herald-Sun* (Melbourne) – 17 November 2013 – A quarter of the nation's health budget is devoted to futile end-of-life care that strips patients of a dignified death and means healthier people have their surgery delayed. In two major studies doctors are pleading for more people to sign advanced care directives that tell medicos not to revive them and not to provide care in certain circumstances. A white paper on End of Life Care, the result of a collaboration of the Australian Centre for Health Research, Monash and Melbourne Universities, says junior doctors are often left in charge of end-of-life care. The paper, to be released on 21 November, said they don't have the authority or confidence to make the tough decisions and instead very frail and elderly people are subjected to "conveyor belt" emergency care that "is reactive, unwanted and unnecessary." And a *Medical Journal of Australia* paper says Australians with advanced disease will average eight hospital admissions in their last year of life - and face a 60-70% chance of dying in a ward. <http://www.heraldsun.com.au/news/national/too-much-medicine-wasted-on-the-dying-endoflife-care-report-says/story-fni0xqrb-1226762059637>

N.B. Links to the white paper on End of Life Care and the *Medical Journal of Australia* paper not available at the time of the distribution if this issue of Media Watch.

Of related interest:

- AUSTRALIA | Australian Institute of Health & Welfare – 15 November 2013 – **'Palliative care hospital admissions rise by half in 10 years.'** The number of palliative care-related hospital admissions rose by 49% between 2001-2002 and 2010-2011, according to a [new] report.¹ The report ... shows that there were around 54,500 palliative care-related admissions to public and private hospitals in Australia in 2010-2011. "Patients aged 75 and over accounted for nearly half of palliative care hospital admissions in 2010-2011," said Institute spokesperson Dr. Pamela Kinnear. Palliative care admissions accounted for 0.6% of all hospital admissions in 2010-2011, but about 37% of patients who died as an admitted patient had been a palliative care patient during their final admission. "About 16,500 patients, representing more than two-thirds of palliative care patients, died with cancer as a principal diagnosis," Dr. Kinnear said. <http://www.aihw.gov.au/publication-detail/?id=60129545247>

1. 'Palliative care services in Australia 2013,' Australian Institute of Health & Welfare, November 2013. <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129545131>

Specialist Publications

'What palliative care can do for motor neurone disease patients and their families' (p.10), in *European Journal of Palliative Care*.

'"Diagnosing dying" in cancer patients: A systematic literature review' (p.10), in *European Journal of Palliative Care*.

'Turf matters: Hospice care in the patient's home' (p.11), in *European Journal of Palliative Care*.

'Jacksplace: A hospice dedicated to teenagers and young adults in Hampshire [England]' (p.15), in *European Journal of Palliative Care*.

'End-of-life care initiative halves patient deaths in [a U.K.] hospital' (p.12), in *GP*.

End-of-life care in Asia

Palliative care "a drop in the ocean," but tide is changing

CAMBODIA | *The Phnom Penh Post* – 15 November 2013 – Palliative care ... is a relatively new concept in Cambodia with few specialist practitioners. Each year thousands of Cambodians die in unnecessary suffering for want of strong pain-killing medication or proper psychological care. Practitioners say barriers to Western-style care for the dying include reliance on families providing care, reluctance on the part of some medical staff to change their practices and to deliver bad news to patients, and – as in every other sector in Cambodia – lack of money. And yet – thanks in large part to *Douleurs Sans Frontières* (Pain Without Borders) – palliative care ideals are gradually coming into practice in Cambodian public hospitals, non-government hospices and patients' homes. According to anthropologist Susan Needham the palliative care ideal of a "good death" is actually very similar to the traditional Cambodian ideal. "From what I understand among Cambodians, it is believed that the moment of death affects the quality of the spirit's afterlife," Needham said. "The goal is to keep people calm and relaxed as they are dying (sounds like a form of palliative care to me)." However, in Cambodian hospitals doctors and nurses are generally responsible only for clinical curative treatment, not "comfort care." Much of what's considered palliative care ... is left to patients' families who are also expected to feed, bathe, toilet and even change the dressings of their loved ones. <http://www.phnompenhpost.com/7days/palliative-care-%E2%80%98-drop-ocean%E2%80%99-tide-changing>

N.B. *Douleurs Sans Frontières* website: <http://douleurs.org/>

Revolution in Tokyo: Emperor, Empress to be cremated and buried in eco-friendly mausoleums

JAPAN | *AsiaNews* (Tokyo) – 15 November 2013 – In what constitutes a break with a 350-year-old tradition, Japan's imperial couple has decided to be cremated after they die. Emperor Akihito and Empress Michiko also expressed a wish to be buried in a smaller eco-friendly mausoleum following funeral services that are as little socially disruptive as possible. The announcement made by the Imperial House has sparked an intense debate in the country, where the imperial family still remains an important symbol of national unity despite losing its semi-divine status. Changes to the funeral rites have been under consideration since April last year after the Emperor and Empress expressed their wish to be cremated, a historic change since the early Edo Period, Imperial Household Agency chief Noriyuki Kazaoka said. The Edo Period is also known as the Tokugawa Period, and represents the final stage in the country's shogunate regime. The decision marks a turning point in Japanese imperial tradition. Usually, when an emperor dies, the whole country goes into mourning for nine days. Following Shinto customs, people make offerings, visit the Imperial Palace to extend their condolences and abstain from normal social life. <http://www.asianews.it/news-en/Revolution-in-Tokyo:-Emperor,-Empress-to-be-cremated-and-buried-in-eco-friendly-mausoleums-29550.html>

Quotable Quotes

I don't want my life to be defined by what is etched on a tombstone. I want it to be defined in what is etched in the lives and hearts of those I've touched. American behavioural scientist, Steve Maraboli, in *Life, the Truth, and Being Free*.

End-of-life care in Ireland

Health Service Executive signs agreement to improve palliative care

IRELAND | *The Journal* (Dublin) – 14 November 2013 – The Health Service Executive has signed a collaborative agreement with the Irish Hospice Foundation to cover cooperation on joint projects to improve palliative care and end-of-life care services in Ireland. The agreement aims to deliver maximum benefits to those accessing palliative care services to avoid unnecessary duplication and maximise opportunities for cross-sector working. The collaboration is on a number of areas, including a review of palliative care for all, primary care, advance care planning, bereavement, and addressing

gaps in the prison service. The Foundation said there is also potential to expand the Hospice Friendly Hospitals programme into community hospitals and work on the development of palliative care [for people] with dementia. <http://www.thejournal.ie/palliative-care-hse-1175383-Nov2013/>

Specialist Publications

'Warning that "living wills" face an "impossible" task' (p.13), in *The Irish Medical Times*.

N.B. Several articles on end-of-life care in Ireland, including one on the Foundation's Hospice Friendly Hospitals programme, are noted in Media Watch, 1 July 2013, #312 (p.6).

Of related interest:

- IRELAND | Oireachtas [Parliamentary] Joint Committee on Health & Children – Accessed 12 November 2013 – **'End of life care in Ireland: Public dialogue.'** The Committee is examining issues relating to dying, death and bereavement while investigating what needs to happen to ensure ... everyone in Ireland has the opportunity to have a good death. It will exam this issue over a broad range of parameters ... examining areas such as planning for end of life; the role of specialist palliative care; dying in hospital, dying at home, and dying in long-stay residential facilities; children; diversity and bereavement care. Submissions and presentations to date: http://www.oireachtas.ie/parliament/oireachtasbusiness/committees_list/health-and-children/submissionsandpresentations/

Family of devout Muslim in minimally conscious state lose right-to-life case

U.K. | *The Guardian* – 13 November 2013 – The family of an elderly devout Muslim who is in a minimally conscious state have lost their legal bid to prolong his life. They argued that the 72-year-old man, who can be identified only as VT, would regard his suffering as bringing him closer to God. The family contested an application by a National Health Service Trust that it was not in VT's best interests for him to be given intensive resuscitation or be admitted to intensive care if his condition deteriorated. But Mr. Justice Hayden, at the court of protection in London, said the Trust could withhold treatment. To prolong life in VT's case would "effectively be restarting a life which has stopped," he said. <http://www.theguardian.com/law/2013/nov/13/family-muslim-lose-right-to-life-case-god>

Noted in Media Watch, 11 November 2013, #331 (p.4):

- U.K. | *The Guardian* – 9 November 2013 – **'Muslim family challenges "do not resuscitate" ruling over gravely ill man.'** A court will decide whether a seriously ill Muslim man should not be revived if his condition deteriorates – against the wishes of his family, who say it is God's will that doctors must do all they can to keep him alive. The case, which will be seen in some quarters as a clash between the state and religion, is the first of its kind to deliver a judgment following a Supreme Court ruling last month that found doctors were right to withdraw treatment from a man in Liverpool. <http://www.theguardian.com/lifeandstyle/2013/nov/09/muslim-family-do-not-resuscitate-challenge-liverpool>

HIV/AIDS epidemic now throws up dilemma of ageing

INDIA | *The Times of India* (Mumbai) – Accessed 11 November 2013 – The HIV/AIDS epidemic it seems is throwing up a new dilemma – of ageing populations living with the virus. "People 50 years and above are frequently being missed by HIV services," said Michel Sidibe, UNAIDS executive director, adding this was costing lives. "Much more attention needs to be given to their specific needs and to integrating HIV services into other health services which people 50 years and over may already have access to," he pointed out. An estimated 3.6 million of the total 35.3 million people living with HIV/AIDS are above 50 years of age, according to a 2013 UNAIDS report. In high-income countries, nearly one-third of the persons living with HIV/AIDS are above 50 years. The "aging" of the HIV epidemic can be attributed to multiple factors including the success of AIDS medication or what is known as antiretroviral therapy in prolonging the lives of those living with HIV/AIDS, the shift of the HIV/AIDS burden to older age-groups, as well as older persons now increasingly indulging in risk-taking behaviour including unsafe sex or needle-related drug use. http://articles.timesofindia.indiatimes.com/2013-11-02/mumbai/43610833_1_the-hiv-aids-unaidsexecutive-director-hiv-epidemic

Noted in Media Watch, 11 November 2013, #331 (p.16):

- *TEACHING SOCIOLOGY* | Online – 28 October 2013 – '**Lessons on stigma: Teaching about HIV/AIDS.**' Teaching about the sociology of HIV/AIDS involves teaching about the causes and effects of stigma. The authors describe a Sociology of HIV/AIDS course at the University of Alabama in which stigma reduction was assessed as a primary objective. <http://tso.sagepub.com/content/early/2013/10/25/0092055X13510412.abstract>

Noted in Media Watch, 4 November 2013, #330 (p.11):

- *THE LANCET* | Online – 21 October 2013 – '**The end of AIDS: HIV infection as a chronic disease.**' For patients who are motivated to take therapy and who have access to lifelong treatment, AIDS-related illnesses are no longer the primary threat. A new set of associated complications have emerged, resulting in a novel chronic disease that for many will span several decades of life. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(13\)61809-7/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)61809-7/abstract)

HIV/AIDS treatment suffers major setback

U.S. (MARYLAND) | *The Pentagon Post* (Baltimore) – 12 November 2013 – In a major setback in the fight against HIV/AIDS, a research finding has suggested the complete treatment of the deadly disease may be a distant dream as scientists have found the reservoir of latent or inactive HIV that silently lingers in a patient's body is much larger than scientists believed.¹ This new report from Howard Hughes Medical Institute has revealed completely eradicating the human immunodeficiency virus may be much more difficult than previously thought. Scientists say, this pool of viruses – known as HIV proviruses – may actually be 60-fold greater than previous estimates. <http://www.pentagonpost.com/hiv-aids-treatment-suffers-major-setback/83414303>

1. 'Replication-competent noninduced proviruses in the latent reservoir increase barrier to HIV-1 cure,' *Cell*, 2013;155(3):540-455. [http://www.cell.com/abstract/S0092-8674\(13\)01157-4](http://www.cell.com/abstract/S0092-8674(13)01157-4)

Specialist Publications

'Do prisoners in South Africa have a constitutional right to a holistic approach to antiretroviral treatment?' (p.16), in *South African Journal of Bioethics & Law*.



Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (SCOTLAND) | *The Scotsman* (Edinburgh) – 14 November 2013 – '**Assisted suicides may be filmed as safeguard.**' A new bill that would allow legally assisted suicide in Scotland will be launched at Holyrood [Scottish parliament] by the independent MSP [Member of the Scottish Parliament] Margo MacDonald. It is Ms. MacDonald's second attempt to change the law after a previous bill was blocked in a free vote during the last parliament. The Lothians MSP has set out key changes to her proposed shake-up in Scotland's suicide laws, which would see government ministers licensing individuals to collect medicine for sick friends and to stay with the patient until they had used the drugs prescribed by a GP to end their life. <http://www.scotsman.com/news/politics/top-stories/assisted-suicides-may-be-filmed-as-safeguard-1-3187740>
- AUSTRALIA (SOUTH AUSTRALIA) | Sky News (Adelaide) – 11 November 2013 – '**New attempt at euthanasia laws.**' The latest attempt to introduce voluntary euthanasia laws in South Australia will play out in state parliament this week. Independent MP Bob Such has introduced his 'Ending Life with Dignity' bill which has recently been revised following consultations with key groups including the South Australian Law Society. Debate and a vote is possible ... with the legislation seeking to give a limited number of competent adults who are in the final phase of a terminal illness and who are suffering unbearable pain the right to make informed choices about the time and manner of their death. It also seeks to ensure that people who have requested euthanasia obtain humane medical assistance to hasten death and that the administration of euthanasia is subject to appropriate safeguards and supervision including the need for two medical opinions. <http://www.skynews.com.au/local/article.aspx?id=923449>

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

Comparison of hospice use by European Americans, African Americans, and Latinos: A follow-up study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 11 November 2013 – Archival data were collected on patients' race/ethnicity, gender, marital status, length of stay in hospice, and reason for discharge. In contrast to previous findings, African Americans were more likely to utilize hospice services, but Latinos were less likely to use hospice services compared to the other groups. There were no differences among the racial/ethnic groups in terms of length of stay or disposition at termination. Strengthening efforts to reach a larger racial/ethnic representation in hospice programs may increase the rate of hospice use by some racial/ethnic groups but not others. <http://ajh.sagepub.com/content/early/2013/11/10/1049909113511143.abstract>

Noted in Media Watch, 7 October 2013, #326 (p.3 & p.8, respectively):

- U.S. (CALIFORNIA) | *New America Media* (San Francisco) – 2 October 2013 – '**Why are Latinos not using palliative and hospice care?**' Latinos, the largest minority in the U.S., are not using hospice services for many reasons. <http://newamericamedia.org/2013/10/why-are-latinos-not-using-palliative-and-hospice-care.php>
N.B. Additional articles on America's Latino population and end-of-life care are noted in Media Watch, 29 July 2013, #316 (p.13).
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 October 2013 – '**Barriers to end-of-life care for African Americans from the providers' perspective: Opportunity for intervention development.**' African Americans are less likely to complete advance directives and enroll in hospice. Barriers included: lack of knowledge about prognosis, desires for aggressive treatment, family members resistance to accepting hospice, and lack of insurance. <http://ajh.sagepub.com/content/early/2013/10/03/1049909113507127.abstract>

N.B. Additional articles on African Americans and end-of-life care are noted in this issue of Media Watch (p.8).

Population ageing: The time bomb that isn't?

BRITISH MEDICAL JOURNAL | Online – 12 November 2013 – The extent, speed, and effect of population ageing have been exaggerated because the standard indicator – the old age dependency ratio – does not take account of falling mortality. When measured using remaining life expectancy old age dependency turns out to have fallen substantially in the U.K. and elsewhere over recent decades and is likely to stabilise in the U.K. close to its current level. The capacity of healthcare systems to cope with increasing longevity will depend on the changing relationship between morbidity and remaining life expectancy and, in particular, the effect of education. <http://www.bmj.com/content/347/bmj.f6598>

End-of-life care in Canada

Defining and measuring a palliative approach in primary care

CANADIAN FAMILY PHYSICIAN, 2013;59(11):1149-1150. The most frequently cited statistic about palliative care in Canada, quoted in numerous publications from Canadian policy makers, politicians, academics, advocates, and the mass media, is that "only 16-30% of those who need it receiv[e] palliative care." The fallacy in this claim, of course, is the implication that all Canadians approaching the end of life should be cared for by specialist palliative care teams. The widely held perception is that primary care's role in providing palliative care is both minor and shrinking, and that the system's response should be to build webs of specialist palliative care to assume responsibility for the growing numbers of these patients. <http://www.cfp.ca/content/59/11/1149.full>

Of related interest:

- *OMEGA – JOURNAL OF DEATH & DYING*, 2013-2014;68(1):23-33. **'Meaning-making and managing difficult feelings: Providing front-line end-of-life care.'** [in one Canadian city]. RCAs [resident care aides, i.e., study participants] spoke of personal challenges involved in witnessing death and experiencing loss, as well as helplessness and frustration when they could not provide quality end-of-life care. They invoked "consoling refrains" to manage grief, including "such is life," "they are better off," and "they had a full life." To manage guilt and moral distress, RCAs reminded themselves "I did my best" and "I experience rewards." <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,5;journal,1,267;linkingpublicationresults,1:300329,1>

Uncertainty in end-of-life care

CURRENT OPINION IN CRITICAL CARE | Online – 11 November 2013 – Uncertainty surrounding medical decision-making is particularly important during end-of-life decision-making. Doubts about the patient's best interests and prognostic accuracy may lead to conflict. Many authors have suggested recently that medical attitudes to uncertainty need review. It is inappropriate to avoid discussion of uncertainty during end-of-life care and American literature suggests that patients and families accept uncertainty in end-of-life discussions. Recently, authors have advocated the concept of "Practical Certainty" accepting that absolute certainty is rarely possible in end-of-life decision-making and openly acknowledging that the physicians are as certain as they can be in the circumstances. Allowing time to provide acceptance of a palliative care pathway and using the collective wisdom of colleagues improves the accuracy of prediction and reduces conflict at the end of life. The implications of this review are that doctors should not avoid discussing uncertainty in end-of-life conversations and the article provides some recommendations for minimizing conflict arising from end-of-life discussion. http://journals.lww.com/co-criticalcare/Abstract/publishahead/Uncertainty_in_end_of_life_care.99576.aspx

Cont.

Of related interest:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(6):292-296. **""Diagnosing dying" in cancer patients: A systematic literature review.** The aim of this systematic literature review was to provide an overview of the published evidence supporting the timely recognition of the entry of cancer patients into the dying phase. Out of 12 eligible studies, only three can be seen as "dying-specific" studies. They did not identify the same phenomena as indicating entry into the dying phase, although there is some overlap. Out of the three "dying-specific" studies, only one addressed the last days of life in cancer patients and integrated "significant factors for predicting dying" into a computer-assisted prediction model. The literature does not provide an adequate basis for a systematic review and the current evidence for both the signs and symptoms of approaching death and the tools to diagnose it is poor. More and better-designed studies are needed to address the lack of data in this field.¹
 1. Access to the *European Journal of Palliative Care* requires a subscription. Contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?pageid=58&JID=4&Year=2013&Edition=488
- *JOURNAL OF HOSPITAL MEDICINE* | Online – 13 November 2013 – **'Caring about prognosis: A validation study of the caring criteria to identify hospitalized patients at high risk for death at 1 year.'** The CARING¹ criteria are a practical prognostic tool validated in a broad inpatient population that can be utilized on hospital admission to estimate risk of death in 1 year, with the goal of identifying patients who may benefit most from incorporating palliative interventions... <http://onlinelibrary.wiley.com/doi/10.1002/jhm.2107/abstract>
 1. C = primary diagnosis of cancer, A = admissions to the hospital for a chronic illness within the last year; R = resident in a nursing home; I = intensive care unit admission with multi-organ failure, NG = non-cancer hospice guidelines.
- *JAMA INTERNAL MEDICINE* | Online – 11 November 2013 – **'Palliative care = Hope.'** This poignant case illustrates some of the barriers to appropriate engagement of a palliative care team. The emergency medicine physician mistakenly equated palliative care with giving up hope. However, hope is not lost when we approach the limits of medical science's capacity to cure disease and prolong life. <http://archinte.jamanetwork.com/article.aspx?articleid=1770518>

What palliative care can do for motor neurone disease patients and their families

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2013;20(6):286-289. Motor neurone disease (MND) is a progressive neurological condition with no cure and a short prognosis. Palliative care involvement is therefore appropriate from the time of diagnosis. The symptoms of MND, which are varied and will worsen as the disease progresses, should be managed appropriately. The psychosocial care needs of patients and their families or carers should be addressed, including when there are concerns regarding a possible genetic cause of the disease. The involvement of the specialist palliative care team may be episodic, occurring at times of change, crisis or decision-making; for example, at diagnosis, when discussing gastrostomy or ventilatory support, when there are cognitive changes and at the end of life. End-of-life care planning – and reassurance that, with good palliative care, death is usually peaceful – is a crucial part of care.¹

1. Access to the *European Journal of Palliative Care* requires a subscription. Contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?pageid=58&JID=4&Year=2013&Edition=488

Noted in Media Watch, 7 January 2013, #287 (p.10):

- *IRISH MEDICAL JOURNAL*, 2012;105(10):335-338. **'A retrospective review of specialist palliative care involvement in motor neurone disease.'** The provision of specialist palliative care to Irish patients suffering from motor neurone disease has not been described in the literature. The purpose of this study was to characterize the care provided at a Dublin hospice. Consecutive referrals between 1st January 1999 and 31st December 2008 were reviewed. <http://www.imj.ie/ViewArticleDetails.aspx?ArticleID=9704>

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Noted in Media Watch, 5 November 2012, #278 (p.8):

- *GRIEF MATTERS: THE AUSTRALIAN JOURNAL OF GRIEF & BEREAVEMENT*, 2012;15(2):32-35. **'Motor neurone disease and palliative care.'** This paper explores the progression of motor neurone disease in order to outline the needs and care requirements with respect to symptoms, suffering, grief and loss, and the potential for early referral to palliative care. <http://search.informit.com.au/documentSummary;dn=828691005476536;res=IELHEA>

Noted in Media Watch, 27 August 2012, #268 (p.11):

- *PALLIATIVE MEDICINE* | Online – 20 August 2012 – **'A 10-year literature review of family caregiving for motor neurone disease: Moving from caregiver burden studies to palliative care interventions.'** This review was consistent with previous research documenting the substantial burden and distress experienced by motor neurone disease family caregivers and revealed important points in the trajectory of care that have the potential for negative effects. <http://pmj.sagepub.com/content/early/2012/08/17/0269216312455729.abstract>

N.B. Additional articles on motor neurone disease and palliative care are noted in this issue of Media Watch (p.11).

"Turf matters"

Hospice care in the patient's home

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2013;20(6):298-299. In a patient's home, hospice care workers are perennially guests and, when delivering care in a family's home, they invariably step into that family's story. Hospice care workers must acknowledge the existence and influence of "turf matters" – each family's history, codes and patterns. They must be cognisant of the internal culture of a home that serves as a social-moral-relational map. End-of-life scenarios pertain to much story-making and storytelling. Hospice care workers bring their own biographical tales into the collaborative plot and therefore need to work on self-awareness and personal development.¹

'The beauty of a sick room': Family care for the dying in the English upper and middle class home c.1840-c.1890

FAMILY & COMMUNITY HISTORY, 2013;16(2): 100-112. With the standard of care provided by hospitals and nursing homes to those nearing the end of their lives the subject of much concern and when increasing numbers of people would like to die at home, it is a timely moment to consider end-of-life care in the 19th century, when death at home was the norm and families had a leading role in providing care. This was also a period of change that laid the foundations for the 20th century model of hospital-centred palliative care. <http://www.ingentaconnect.com/content/maney/fch/2013/00000016/00000002/art00003>

1. Access to the *European Journal of Palliative Care* requires a subscription. Contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?pageid=58&JID=4&Year=2013&Edition=488

Of related interest:

- *JOURNAL FOR THE STUDY OF SPIRITUALITY*, 2013;3(1):33-45. **'Identification of spiritual and religious needs of terminally ill patients receiving palliative home-care.'** In the 1960s, the socio-religious culture [in Quebec, Canada] was so closely linked to the Christian tradition that it provided patients with the words to express their needs which, in turn, were generally articulated through sacramental requests. This research suggests that for a majority of patients today, spiritual and religious needs are expressed through everyday words, for example, through their fears, their questions, their anger, their joy, etc., related to their past experiences (past), to what they are living now (present), and to what they will become (future). <http://essential.metapress.com/content/bh6780k5q668788h/>

Cont.

- *NURSING CHILDREN & YOUNG PEOPLE*, 2013;25(9):31-36. **'Grief and the experiences of nurses providing palliative care to children and young people at home.'** Nurses experienced considerable internal and external pressures. Some are inevitable but others, such as organisation of care provision to families and nurses' personal coping, could be improved by adequately resourced workforces, integrated service structures, and guidance on reflective practice. <http://rcnpublishing.com/doi/abs/10.7748/ncyp2013.11.25.9.31.e366>

End-of-life care initiative halves patient deaths in [a U.K.] hospital

GP | Online – 11 November 2013 – Coastal Medical Group in Morecambe, Lancashire, halved the numbers of its terminally ill patients dying in hospital and almost doubled the number dying in their normal residence. It followed a push by practice staff to seek special palliative care training and accreditation by the National Gold Standards Framework in End of Life Care.¹ Dr. Andrew Foster, a partner at the practice, told *GP* more practices could help patients plan their end-of-life care by working towards the standards. Nationally, about 51% of people die in hospital, despite most people wanting to die at home. <http://www.gponline.com/News/article/1220357/end-of-life-care-initiative-halves-patient-deaths-hospital/>

1. National Gold Standards Framework in End of Life Care website: <http://www.goldstandardsframework.org.uk/>

Turning a tragedy into a tribute: A literature review of creating meaning after loss of a loved one

ILLNESS, CRISIS & LOSS, 2013;21(4):325-340. Death creates a strong emotional impact, and we are powerless to its force and influence. However, it is an experience that can and has been transcended. People can flourish and thrive after the death of a loved one. Creating meaning is defined as people remembering their deceased loved one in ways that add value to their life and the memory of their deceased loved one. This can be done through artistic expressions and various other methods. By inspiring meaning, the survivor perpetuates the value and importance of the loved one's life by living out that meaning. Living out meaning involves the courage to overcome the pain of loss while continuing to affirm inwardly that life with all its sorrows is good. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,5,11;journal,1,76;linkingpublicationresults,1:103734,1>

Of related interest:

- *OMEGA – JOURNAL OF DEATH & DYING*, 2013-2014;68(1):1-22. **""I was just trying to stick it out until I realized that I couldn't": A phenomenological investigation of support seeking among older adults with complicated grief.** Five primary themes arose: 1) observing that grief was causing a great deal of distress and impairment; 2) grief not meeting expectations of what grief "should be"; 3) an important influence of social relationships on support-seeking; 4) lack of effectiveness of grief support groups and/or care from mental health professionals prior to study enrollment; and, 5) strong reactions to the label of CG [complicated grief]. Themes may help inform efforts to engage older adults with CG in effective care. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,1,5;journal,1,267;linkingpublicationresults,1:300329,1>

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

Palliative Care Network-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, exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

Warning that "living wills" face an "impossible" task

THE IRISH MEDICAL TIMES | Online – 14 November 2013 – Advance care directives require people to project themselves psychologically and emotionally into a future situation they cannot imagine, which is an "impossible" task, a palliative care consultant has warned. Dr. Tony O'Brien, Palliative Care Consultant, Cork University Hospital and Marymount Hospice, Cork, said he supported "the process" of advance care directives, such that people should engage with family members and doctors, "and speak in general terms about what they believe their wishes might be." However, he advised that people "change over time" and could come to enjoy a "good quality of life" in circumstances that may have previously surprised them. Dr. O'Brien also expressed concern over the fact that legally-binding advance care directives would be "open to legal challenge" and the courtroom was "the very last place you want these kinds of sensitive, delicate issues addressed." He foresaw that issues would arise regarding definitions of conditions and states of illness. Advance care directives are legally binding in Irish law, but there is currently no legislation covering this area, with the Assisted Decision Making (Capacity) Bill due to incorporate provisions. According to a Medical Council discussion document, it is presently difficult to state the legal position in Ireland "as there have been no cases directly in point in this jurisdiction, nor are there any relevant statutory provisions." <http://www.imt.ie/news/latest-news/2013/11/warning-that-living-wills-face-an-impossible-task.html>

Of related interest:

- *AUSTRALIAN MEDICAL JOURNAL*, 2013;199(10):662-666. **'Difficult but necessary conversations – the case for advance care planning.'** Regardless of potential benefits, ACP [advance care planning] uptake in Australia has been slow, despite widespread professional and public endorsement coupled with supporting legislation in every state and territory. However, many hospitals and nursing homes are now implementing ACP programs, most along the lines of the Respecting Patient Choices program initiated at Austin Hospital in 2002. <https://www.mja.com.au/journal/2013/199/10/difficult-necessary-conversations-case-advance-care-planning>

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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.

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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.

- *THE HEALTH CARE MANAGER*, 2013;32(4):370-379. **'The use of innovative advance directives programs in nursing homes [in the U.S.]'** End-of-life service providers continue to seek improved instruments for individuals to convey their last wishes. This project explores the relationship of nursing home profit status and innovativeness to the use of these advance directive programs (ADPs) ... to determine what other types of innovations are associated with the use of these ADPs and the differences in use by nursing home characteristics. http://journals.lww.com/healthcaremanagerjournal/Abstract/2013/10000/The_Use_of_Innovative_Advance_Directives_Programs.11.aspx
- *PATIENT EDUCATION & COUNSELING* | Online – 9 November 2013 – **'Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making.'** Many barriers are potentially modifiable, and can be addressed by attitudinal changes at the levels of patient, clinician/healthcare team, and the organization. The results support the view that many patients currently can't participate in shared decision making, rather than they won't participate because they do not want to. <http://www.sciencedirect.com/science/article/pii/S0738399113004722>

The frequency and cost of treatment perceived to be futile in critical care

JAMA INTERNAL MEDICINE, 2013;173(20):1887-1894. During a 3-month period, there were 6,916 assessments by 36 critical care specialists of 1,136 patients. Of these patients, 904 (80%) were never perceived to be receiving futile treatment, 98 (8.6%) were perceived as receiving probably futile treatment, 123 (11%) were perceived as receiving futile treatment, and 11 (1%) were perceived as receiving futile treatment only on the day they transitioned to palliative care. Patients with futile treatment assessments received 464 days of treatment perceived to be futile in critical care (range, 1-58 days), accounting for 6.7% of all assessed patient days in the 5 ICUs studied. Eighty-four of the 123 patients perceived as receiving futile treatment died before hospital discharge and 20 within 6 months of ICU care (6-month mortality rate of 85%), with survivors remaining in severely compromised health states. The cost of futile treatment in critical care was estimated at \$2.6 million. <http://archinte.jamanetwork.com/article.aspx?articleid=1735897>

Of related interest:

- *ZDRAVNIŠKI VESTNIK* (Slovenian Medical Journal), 2013;82(9):589-601. **'End-of-life ethical dilemmas in intensive care unit.'** The decision regarding continuing or stopping treatment should be based on careful evaluation of the balance between its expected efficiency and benefits on the one hand and the burden imposed upon the patient on the other. If the burden clearly exceeds the expected benefits, the ethically sound decision is to terminate such treatment. <http://www.cabdirect.org/abstracts/20133375925.html;jsessionid=C1C595910A7999928DE00FE5E0E65BF8>

Pediatric hospice care knowledge: A transaction cost perspective

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2013;15(8):485-490. With the passage of the [U.S.] Patient Protection & Affordable Care Act of 2010, hospice care for children changed. The change in the hospice eligibility rule for children is expected to increase hospice utilization, and hospices will now be faced with acquiring pediatric hospice care knowledge either internally or externally. This article sought to predict, using transaction cost analysis, which hospices will acquire pediatric knowledge internally compared with purchasing knowledge through the external market. A set of propositions was developed about how transaction characteristics (i.e., frequency, asset specificity, uncertainty) may affect the internal or external acquisition of pediatric hospice care knowledge. The analysis revealed that there is a greater probability of hospices acquiring internal pediatric hospice care knowledge in an environment of high frequency, high asset specificity, and high uncertainty. This study has implication for hospice and palliative care nurses. http://journals.lww.com/jhpn/Abstract/2013/12000/Pediatric_Hospice_Care_Knowledge_A_Transaction.12.aspx

Cont.

Of related interest

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2013;15(8): 464-470. **'Victor and the Dragon: A young child's experiences of discomfort and comfort, from diagnosis until death.'** Conversations, field notes, drawings, and interviews with the child and his mother and nurse were analyzed. The themes "enduring unbearable situations," "expressing emotional suffering," and "finding comfort" were constructed. The children's parents and other family members are often a significant source of help for the children to endure discomfort and find comfort. Emotional suffering can be expressed in drawing and crying, but sometimes, a child is inconsolable and must endure discomfort. Comfort for a dying child is enhanced by having the family close, experiencing normal daily activities such as drawing and playing, and feeling at home in life despite approaching death. http://journals.lww.com/jhpn/Abstract/2013/12000/Victor_and_the_Dragon_A_Young_Child_s_Experience_s.9.aspx

Jacksplace – a hospice dedicated to teenagers and young adults in Hampshire [England]

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2013;20(6):277-279. Jacksplace ... is one of only three purpose-built hospices for teenagers and young people in the U.K. Housed in a well planned building, Jacksplace provides respite care for patients up to the age of 25 and end-of-life care up to the age of 30, for all types of life-limiting or life-threatening conditions. Many parents and teenagers find the transition from paediatric to adult services difficult, and Jacksplace has been confronted with issues regarding transition and adaptation to an adult care setting. Now in its fourth year, Jacksplace is finding its identity. Its vibrancy and modernity make it stand out from traditional adult hospices.

N.B. Access the *European Journal of Palliative Care* requires a subscription. Contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?pageid=58&JID=4&Year=2013&Edition=488

Determinants of the administration of continuous palliative sedation: A systematic review

JOURNAL OF PALLIATIVE MEDICINE | Online – 14 November 2013 – Little is known about the determining factors related to the administration of continuous palliative sedation. Knowledge of these determinants may assist physicians in identifying patients who are at high risk of developing refractory symptoms, enable physicians to inform patients, and optimize close monitoring. In total, eight papers were reviewed. The following nine factors were found to be associated with the administration of continuous palliative sedation: younger age, male sex, having cancer, feelings of hopelessness, dying in a hospital, living in a Dutch speaking community setting, very non-religious or extremely non-religious physicians, physicians working in "other hospital" specialties, and physicians in favor of assisted death. Given the variation in study designs and the limitations of the included studies, the outcomes should be interpreted carefully. Further research is needed... <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0173>

Noted in Media Watch, 4 November 2013, #330 (p.8):

- *INTERNATIONAL JOURNAL OF CLINICAL PRACTICE*, 2013;67(11):1086-1088. **'Clinical and ethical challenges of palliative sedation therapy: The need for clear guidance and professional competencies.'** Palliative sedation therapy (PST) has become a frequent practice in end-of-life care and advocated in the literature as a less problematic alternative to practices of physician-assisted dying, such as ending patients' lives on request, or assisted suicide. <http://onlinelibrary.wiley.com/doi/10.1111/ijcp.12227/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Moving upstream: A review of the evidence of the impact of outpatient palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 13 November 2013 – There is good evidence for the efficacy of inpatient palliative care in improving clinical care, patient and provider satisfaction, quality of life, and health care utilization. However, the evidence for the efficacy of non-hospice outpatient palliative care is less well known and has not been comprehensively reviewed. Four well-designed randomized interventions as well as a growing body of non-randomized studies indicate that outpatient palliative care services can: 1) improve patient satisfaction; 2) improve symptom control and quality of life; 3) reduce health care utilization; and, 4) lengthen survival in a population of lung cancer patients. The available evidence supports the ongoing expansion of innovative outpatient palliative care service models throughout the care continuum to all patients with serious illness. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0153>

Noted in Media Watch, 4 March 2013, #295 (p.5):

- *BMC PALLIATIVE CARE* | Online – 21 February 2013 – '**International recommendations for outpatient palliative care and pre-hospital palliative emergencies: A prospective questionnaire-based investigation.**' Survey responses were obtained from 35 different countries. This study detected structurally and nationally differences in outpatient palliative care regarding the treatment of palliative emergencies. <http://www.biomedcentral.com/content/pdf/1472-684X-12-10.pdf>

Noted in Media Watch, 24 December 2012, #285 (p.9):

- *ONCOLOGY TIMES*, 2012;34(24):24-27. '**Palliative care pushing into outpatient settings.**' The [U.S.] Center to Advance Palliative Care has launched a new initiative to improve palliative care in cancer care clinics and other outpatient settings. http://journals.lww.com/oncology-times/Fulltext/2012/12250/Palliative_Care_Pushing_into_Outpatient_Settings.6.aspx

Information needs of family carers of people with diabetes at the end of life: A literature review

JOURNAL OF PALLIATIVE MEDICINE | Online – 12 November 2013 – Sixteen of the more than 300 papers identified addressed the information needs of family carers of people with diabetes at the EOL [end of life] and were included in the review. Five key themes were identified from the papers reviewed: 1) performing diabetes care tasks; 2) focus of care; 3) blood glucose management; 4) EOL stages; and, 5) involving patients and family carers in decisions about diabetes care. Most of the 16 papers represented the views of health professionals and focused on the need to provide information about the medical aspects of diabetes management. The review suggests further research is needed to identify the information needs of family carers of people with diabetes at the EOL to enable interventions to be developed to support the family carers and meet their unique information needs. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0265>

Do prisoners in South Africa have a constitutional right to a holistic approach to antiretroviral treatment?

SOUTH AFRICAN JOURNAL OF BIOETHICS & LAW, 2013;60(2):40-44. The prevalence of AIDS in prisons is believed to be higher than in the broader community. While the courts have used their powers to enforce prisoners' rights in terms of the Constitution, specifically their right to medical treatment, the state needs to adopt a holistic approach when providing antiretroviral therapy (ART) for prisoners. Failing to provide support for ART, beyond its mere provision, would offend the values of the Constitution. This support includes comprehensive HIV and AIDS care and prevention, treatment of opportunistic infections, access to nutritional supplements, access to palliative care and compassionate release. Counteracting challenges to the implementation of effective treatment, care and support strategies will require committed endeavours by the Department of Correctional Services. <http://www.ajol.info/index.php/sajbl/article/view/96484>

Does it matter what you call it? A randomized trial of language used to describe palliative care services

SUPPORTIVE CARE IN CANCER, 2013;21(2):3411-3419. When compared to palliative care, the term supportive care was associated with better understanding, more favorable impressions, and higher future perceived need. There was no difference in outcomes between traditional and patient-centered descriptions. In adjusted linear regression models, the term supportive care remained associated with more favorable impressions and higher future perceived need when compared to palliative care. <http://link.springer.com/article/10.1007/s00520-013-1919-z>

Articles on defining end-of-life care noted in past issues of Media Watch:

- *THE ONCOLOGY REPORT* | Online – 10 April 2013 – **'Is the moniker "palliative care" too loaded?'** A survey of 169 patients with advanced cancer found those randomized to hear the term "supportive care" instead of "palliative care" rated their understanding, overall impressions and future perceived need for those services significantly higher. [Noted in Media Watch, 15 April 2013, #301 (pp.14-15)] <http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/what-s-in-a-name-is-the-moniker-palliative-care-too-loaded/15b05715fc83fdc88503a88bc9cbfc0e.html>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 11 January 2013 – **'Medical oncologists' perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process. A qualitative study.'** Although most [study participants] claimed that early referrals to the service are preferable, oncologists identified several challenges, related to the timing and communication with patients regarding the referral... [Noted in Media Watch, 14 January 2013, #288 (p.7)] <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8814761&fulltextType=RA&fileId=S1478951512000685>
- *PLoS ONE* | Online – 3 July 2013 – **'Diversity in defining end-of-life care: An obstacle or the way forward?'** Responses to a survey were received from 167 individuals, mainly from academics (39%) and clinical practitioners working in an academic context (23%) from 19 countries in Europe and beyond. Two approaches were identified to arrive at an understanding of EoL care: exclusively by drawing boundaries through setting time frames, and inclusively by approaching its scope in an integrative way. This led to reflections about terminology and whether defining EoL care is desirable. [Noted in Media Watch, 15 July 2013, #314 (p.13)] <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0068002>
- *SUPPORTIVE CARE IN CANCER* | Online – 31 August 2012 – **'Concepts and definitions for "supportive care," "best supportive care," "palliative care," and "hospice care" in the published literature, dictionaries, and textbooks.'** Commonly used terms such as "supportive care," "best supportive care," "palliative care," and "hospice care" were rarely and inconsistently defined in the palliative oncology literature. [Noted in Media Watch, 3 September 2012, #269 (p.7)] <http://link.springer.com/article/10.1007/s00520-012-1564-y>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(6):266-272. **'Assisted dying – the current situation in Flanders: Euthanasia embedded in palliative care.'** In Belgium, a law decriminalising euthanasia was passed in 2002. Palliative care professionals in Flanders are now practising "euthanasia accompaniment," supporting people who request euthanasia in all aspects of care. This takes place in full respect of each practitioner's choice regarding their involvement. The introduction of euthanasia forced palliative care to develop further, which is a positive consequence; however, there are also some negative consequences: legalism and proceduralism; euthanasia following its own course; and instrumentalisation.¹

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- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(6):273-276. 'Commentary on 'Assisted dying – the current situation in Flanders: Euthanasia embedded in palliative care.'" In the preceding article the authors describe how euthanasia has come to be incorporated into palliative care provision in Flanders and, to some extent, in the whole of Belgium. This commentary offers a critique of the situation described and questions many of the assumptions behind the Belgian model.¹

1. Access to the *European Journal of Palliative Care* requires a subscription. Contents page:
http://www.haywardpublishing.co.uk/year_search_review.aspx?pageid=58&JID=4&Year=2013&Edition=488

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2013/11/media-watch/>

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

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

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

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/>

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

Australia

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

Canada

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpcconnection.ca/newsletter/inthenews.html>

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

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.palliativecareconsultation.ca/?q=mediawatch>

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/news-events>

Europe

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> (Scroll down to 'Media Watch')

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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