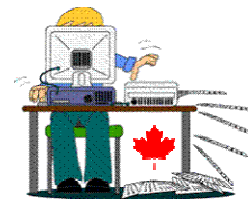


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to [Specialist Publications](#) and 'Does the use of specialist palliative care services modify the effect of socioeconomic status on place of death? A systematic review' (p.16), in *Palliative Medicine*.

Canada

Assisted (or facilitated) death: Representative sample of recent news media coverage

Medical leaders grapple with new euthanasia dilemma: What to write on the death certificate

THE NATIONAL POST | Online – 4 September 2015 –As Canada inches closer to granting doctors the power to end the lives of consenting patients, medical leaders are grappling with a new dilemma: should deaths by lethal injection be classified “death by natural causes” on death certificates? Quebec’s College of Physicians is considering recommending doctors list the underlying terminal disease as the cause of death in cases of “medical aid in dying” on public death records – and not euthanasia. The college says it wants to ensure life insurance is paid to families in cases of euthanasia and says the province’s assisted-death law will require any doctor who administers euthanasia to report the death to a special oversight body. <http://news.nationalpost.com/health/medical-leaders-grapple-with-new-euthanasia-dilemma-what-should-be-on-the-death-certificate>

Related:

- *THE GLOBE & MAIL* | Online – 3 September 2015 – ‘**Where federal parties stand on physician-assisted death.**’ Life’s two great certainties are emerging as election issues: taxes, because of the technical recession, and death, because the population is aging. The economy will affect more people, but old people vote and they want to know where the warring [i.e., Conservative, Liberal, New Democratic, and Green] parties stand on implementing the Supreme Court of Canada’s ruling on physician-assisted death. <http://www.theglobeandmail.com/life/health-and-fitness/health/where-federal-parties-stand-on-physician-assisted-death/article26213288/>
- QUEBEC | CBC News (Montreal) – 2 September 2015 – ‘**Gaétan Barrette insists dying patients must get help to ease suffering.**’ Terminally ill patients in Quebec who seek medical aid in dying must be provided with the service even if some doctors are against it, Quebec’s health minister said... Gaétan Barrette called out unco-operative doctors and directors of institutions in the province’s health care network ... after a palliative care unit in Montreal announced it wouldn’t offer the service. Quebec’s right-to-die law comes into effect on 10 December and Barrette says the patient will be the priority.

Cont.

Only certain terminally ill people will receive the legal right to seek medical aid in dying and the strict law states those patients must be at death's door and suffering. The health minister declared that hospitals with palliative care units as well as palliative care homes must conform with the law and offer medical assistance to dying patients who ask for it. Barrette says that on an individual basis, a doctor could invoke an objection of conscience and refuse to shorten the life of a sick person. But he insists that the institution must respond to the request and find another doctor willing to offer the service. <http://www.cbc.ca/news/canada/montreal/ga%C3%A9tan-barrette-insists-dying-patients-must-get-help-to-ease-suffering-1.3213615>

- QUEBEC | CBC News (Montreal) – 2 September 2015 – **‘Palliative care centres say no to medically assisted death.’** The director of the West Island Palliative Care Residence says patients seeking assistance with dying will have to go elsewhere. “We are absolutely one of the 29 [palliative care programs in Quebec] that are opting out of providing this service,” says the residence’s executive director, Theresa Dellar. Dellar said patients at the palliative care residence who request medically assisted death will be transferred out to another facility where their wishes can be carried out, with no judgment... However, she said, there needs to be a stronger case made for palliative care in Quebec. She said only a fraction of Quebecers have access to palliative care, but Quebec’s new law on allowing for medical help in dying makes that option available to 100% of Quebecers. “Right now only 16% of Canadians have access to palliative care, so how can they make that choice?” <http://www.cbc.ca/news/canada/montreal/palliative-care-dying-with-dignity-quebec-1.3212672>

Access to palliative care in Canada

It is generally accepted that the percentage of people living with a terminal illness who have access to palliative care varies greatly across Canada.

In 2005, Senator Sharon Carstairs, Canada’s first and only Minister with Special Responsibility for Palliative Care (2001-2003), had estimated that no more than 15% of Canadians had access to palliative care. In 2007, in the only statistically significant study published to date, the Canadian Institute for Health Information estimated that people living with a terminal illness in British Columbia, Alberta, Saskatchewan and Manitoba were referred to palliative care only 35-37% of the time. This went to a low of 16% if the terminal illness was *not* cancer. A 2009 Université Laval press release estimated the number at 10%.

In recent years, the Canadian Hospice Palliative Care Association estimates have varied from a low of 15% to a high of 30%. The Quality of End-of-Life Care Coalition of Canada has been even less specific – “only a small portion of those who die receive palliative care.”

Access to pediatric palliative care? A 2007 study indicated that “only a small percentage (5-12%) of children who die in Canada receive specialized end-of-life care.” **BRA**

- CTV NEWS | Online – 31 August 2015 – **‘Assisted-death panel defends independence as group travels to Europe.’** The chair of an outside group established to report on the contentious issue of doctor-assisted death is defending his panel’s independence as it embarks on an 11-day research tour in Europe. Harvey Max Chochinov, the Canada research chair in palliative care at the University of Manitoba, says the federal government has selected panellists who intend to be objective. In July, the Conservative government established the panel to solicit attitudes and opinions of Canadians and key stakeholders after the Supreme Court of Canada recognized the right of clearly consenting adults who endure intolerable physical or mental suffering to end their lives with a physician’s help. The panel’s mandate is to establish key findings and options for the cabinet to review, but it has been criticized ... because two of its three members were federal witnesses who argued against assisted suicide when the case was heard. <http://www.ctvnews.ca/health/assisted-death-panel-defends-independence-as-group-travels-to-europe-1.2541414>

Noted in Media Watch, 27 July 2015, #420 (p.2):

- **THE TORONTO STAR** | Online – 23 July 2015 – **‘Peter MacKay says assisted-death panel won’t determine government’s response.’** Panellists tasked with consulting Canadians on the highly controversial issue of doctor-assisted death won’t dictate the government’s response to the Supreme Court’s ruling on the matter... <http://www.thestar.com/news/canada/2015/07/23/peter-mackay-says-assisted-death-panel-wont-determine-governments-response.html>

Cont.

- *THE GLOBE & MAIL* | Online – 31 August 2015 – ‘**Court has ruled on assisted death, but Canada is not prepared.**’ On 6 February 2016 – one year after the historic Supreme Court ruling in the case of Kathleen Carter and Gloria Taylor – physician-assisted death will be legal in Canada. The Canadian Medical Association last week debated what life would be like for physicians and patients in this brave new world. One thing was clear: We are woefully unprepared for 7 February. The thorny question for many doctors is referral. If a patient requests assisted death, do they have an obligation to refer to a doctor who will perform the act? Some physicians see this as morally equivalent to administering a lethal drug. And many physicians who have no problem referring feel that mandating them to perform specific tasks undermines their independence. <http://www.theglobeandmail.com/globe-debate/court-has-ruled-on-assisted-death-but-canada-is-not-prepared/article26167297/>
- *THE NATIONAL POST* | Online – 28 August 2015 – ‘**Quebec doctors to get standard euthanasia kits as province prepares to legalize “medical aid in dying.”**’ The Collège des médecins du Québec has developed a new guideline for doctors unlike any in the history of Canadian medicine: a step-by-step guide to follow before, during and after administering euthanasia to an eligible patient, including the type of drugs to be used, the dose, the injection site and what to do in the event of complications. The guideline, which was developed in collaboration with the Order of Pharmacists of Quebec and the Order of Nurses of Quebec, will be available to doctors, nurses and other health professionals on a secure area of the college’s website. <http://news.nationalpost.com/health/quebec-doctors-to-get-standard-euthanasia-kits>

Noted in Media Watch, 31 August 2015, #425 (p.3):

- CTV NEWS | Online – 25 August 2015 – ‘**Doctors group looking at intensive course to train willing MDs in assisted death.**’ Doctors who are willing to assist in a patient’s death once the act becomes legal early next year will need to be trained because they’ve never been taught the procedures for ending a life, the Canadian Medical Association says. <http://www.ctvnews.ca/health/doctors-group-looking-at-intensive-course-to-train-willing-mds-in-assisted-death-1.2532609>

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

- ONTARIO | CBC News – 14 August 2015 – ‘**Ontario forms expert panel on assisted dying.**’ The Ontario government is setting up an advisory group to study physician-assisted dying, leading 11 provinces and territories in examining the controversial subject. The panel is similar to the one established by the federal government to inform its end-of-life legislation. The federal, provincial and territorial governments will need to craft laws around the court ruling by February 2016, when the ruling takes effect. Ontario and the participating provinces and territories say the primary responsibility to provide health care resides with them, and the panel will craft their response to the court ruling. <http://www.cbc.ca/news/canada/toronto/ontario-forms-expert-panel-on-assisted-dying-1.3191186>

U.S.A.

Senate approves ‘Right-to-Try Act’ for seriously ill

CALIFORNIA | *The Los Angeles Times* – 1 September 2015 – The state Senate ... approved a bill that would allow makers of experimental drugs to make them available to Californians with life-threatening diseases. The measure, which goes back to the Assembly for action on amendments, applies to drugs, devices and biological products that have undergone clinical trials, but have not yet been approved for general public use by the U.S. Department of Agriculture [sic]. <http://www.latimes.com/local/political/la-me-pc-senate-approves-right-to-try-legislation-for-seriously-ill-20150901-story.html>

Noted in Media Watch, 31 August 2015, #425 (p.12):

- *DEATH STUDIES* | Online – 27 August 2015 – ‘**Right-to-try laws and individual patient “compassionate use” of experimental oncology medications...**’ Sixteen U.S. states recently passed “right-to-try” legislation aimed at promoting the U.S. Food & Drug Administration’s Expanded Access Program ... [which] ... could undermine clinical trials that benefit public health. Moreover, existing norms in oncologic care often lead patients to pursue intense treatments near the end of life, at the expense of palliation... <http://www.tandfonline.com/doi/full/10.1080/07481187.2015.1077356#abstract>

Physicians avoid conversations about religion in the ICU

TIME MAGAZINE | Online – 31 August 2015 – Religion and spirituality are not common topics of discussion in intensive care units, and doctors often go out of their way to avoid them – even though religion is often very important to patients and their medical surrogates during end-of-life care.¹ The researchers found that although religion was considered important to 77.6% of the surrogates (a surrogate is a family member or another person responsible for making medical decisions for a patient), conversations about religious and spiritual topics occurred in less than 20% of the goals-of-care conversations. Health care professionals rarely “explored the patient’s or family’s religious or spiritual ideas.” When conversations about spirituality did occur in some of these end-of-life care conversations, the researchers found that 65% of the time the topic was initiated by the surrogate. Health care professionals raised the issue of spirituality only

5.6% of the time. The most common response among health care providers when a surrogate brought up religion or spirituality was to change the subject. <http://time.com/4017141/physicians-religion-icu/>

Specialist Publications

‘The next era of palliative care’ (p.11), in *Journal of the American Medical Association*.

Integrating palliative care into the oncology clinic: A joint management approach’ (p.15), in *Palliative Medicine*.

‘An international comparison of costs of end-of-life care for advanced lung cancer patients using health administrative data’ (p.17), in *Palliative Medicine*.

1. ‘Health care professionals’ responses to religious or spiritual statements by surrogate decision makers during goals-of-care discussions,’ *JAMA Internal Medicine*, 31 December 2015. A multicenter study conducted between October 2009 and October 2012 regarding 249 goals-of-care conversations between 651 surrogate decision makers and 441 health care professionals in thirteen intensive care units across the U.S. <http://archinte.jamanetwork.com/article.aspx?articleid=2430795>

N.B. Commentary on ‘Religion, spirituality, and the intensive care unit: The sound of silence,’ *JAMA Internal Medicine*: <http://archinte.jamanetwork.com/article.aspx?articleid=2430791>

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

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | *Berkeley News* – 3 September 2015 – **‘Californians support medical aid in dying for terminally ill.’** Californians overwhelmingly support medical aid in dying for terminally ill people, according to a new poll by the Institute of Governmental Studies at University California Berkeley. Strong majorities in both major political parties and among independent voters back the idea, as do people in most other demographic categories. Support is noticeably lower only among African Americans, but a narrow majority is in favor. <http://news.berkeley.edu/2015/09/03/igs-poll-californians-support-medical-aid-in-dying-for-terminally-ill/>

Related:

- CALIFORNIA | Reuters – 1 September 2015 – **‘California assisted suicide bill to be heard in special session.’** A controversial bill to allow physician-assisted suicide for terminally ill patients in California comes up for a new round of hearings ... after failing in the legislature earlier this summer amid opposition from the Catholic Church. <http://www.reuters.com/article/2015/09/01/us-usa-california-assisted-suicide-idUSKCN0R13JT20150901>

International

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

Families of dying excluded from “critical conversations”

U.K. (England, Northern Ireland, Scotland, Wales) | *The Belfast Telegraph* – 3 September 2015 – The families of people who are dying are too often excluded from “critical conversations” about what happens at the end of life, experts have warned. More needs to be done to involve the dying and their loved ones to ensure people have the death they want... Dr. Jonathan Koffman, senior lecturer in palliative care at King’s College London, said a round 500,000 people die in England every year, with around a fifth dying from cancer. “How will we identify these individuals and provide them with impeccable assessment?,” he said, adding “you can’t undo these moments.” He said National Health Service care was variable for those who were dying and there were examples of poor care. “There’s inconsistency and poor quality care meted out to people at critical moments in their life,” he said. “Then there’s poor management of really distressing symptoms. This is not a vocal constituency – they can’t talk. And, of course, the family members who are subsequently bereaved are too wounded by those experiences to then talk and help us work out what to do better.” Around 50% of people die in hospital despite the fact most want to die at home, Dr. Koffman said. <http://www.belfasttelegraph.co.uk/news/uk/families-of-dying-excluded-from-critical-conversations-31500173.html>

End-of-life care in Uganda

Palliative care experts call for better access to morphine

UGANDA | *The Observer* (Kampala) – 2 September 2015 – Palliative care experts across Uganda have called for better access to medical morphine and quality palliative care for patients with terminal illnesses... According to the ‘Treat the Pain’ program being implemented in the country by the American Cancer Society, over 69,000 patients in Uganda require morphine annually for moderate to severe pain. Although Moses Kamabare, the general manager of National Medical Stores (NMS), claims that the drug has been dispensed across licensed hospitals and health centres countrywide, testimonies on the ground differ. Previously, NMS has strictly regulated the dispensation of morphine given its psychotropic side effects and only medical doctors, dental surgeons and veterinary doctors were licensed to administer it. However, now under the new Narcotic Drug & Psychotropic Substances Control Act (2015) clinical officers and nurses are permitted to administer morphine. <http://www.observer.ug/lifestyle/39622-palliative-care-experts-call-for-better-access-to-morphine>

Specialist Publications

‘Palliative care in hospital: Why is it so difficult?’
(p.16), in *Palliative Medicine*.

Elder care in England

More male care workers needed, says providers’ chief

U.K. (England) | BBC News – 31 August 2015 – More male care workers are needed to look after older people, the chief executive of Care England has said. An increasing number of men are living longer, more men are needed for their personal care. “We have an ageing population and a lot of people who receive care into old age now are men,” said Professor Martin Green. “The majority of carers are women. When it comes to personal care in particular, some men prefer this to be done by a male rather than female.” Government statistics show 84% of carers across the sector in England are women, and just 16% are men. This figure has remained static since 2012. <http://www.bbc.com/news/uk-34103302>



Cont.

Noted in Media Watch, 23 March 2015, #402 (p.9):

- **THE LANCET** | Online – 8 March 2015 – ‘**Closing the divide: The Harvard Global Equity Initiative – Lancet Commission on global access to pain control and palliative care.**’ In low-income and middle-income countries regulations hampering opioid accessibility, combined with the scarcity of trained doctors and other health professionals, has stymied delivery of pain treatment and palliative care. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)60289-6/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)60289-6/fulltext)

Noted in Media Watch, 9 June 2014, #361 (p.8):

- **UGANDA** | BBC News – 2 June 2014 – ‘**How Ugandan hospice makes cheap liquid morphine.**’ The lack of access to pain relief for dying patients around the world is a public health emergency. The Worldwide Palliative Care Alliance says the restrictions on these drugs are in place because of exaggerated fears about patients becoming addicted. Hospice Africa makes all of Uganda’s liquid morphine. <http://www.bbc.com/news/health-27664121>

Noted in Media Watch, 20 January 2014, #341 (p.9):

- **ANNALS OF ONCOLOGY**, 2013;24(suppl11):xi7-xi13. ‘**The Global Opioid Policy Initiative project to evaluate the availability and accessibility of opioids for the management of cancer pain in Africa, Asia, Latin America and the Caribbean, and the Middle East: Introduction and methodology.**’ Data provided highlight, on a country-by-country basis, issues in formulary inadequacy, problems with cost to consumer and actual availability of medication, and the extent of regulatory barriers... http://annonc.oxfordjournals.org/content/24/suppl_11/xi7.full.pdf+html

India top court lifts ban on Jains’ santhara death fast

INDIA | BBC News – 31 August 2015 – India’s Supreme Court has suspended an order of the Rajasthan high court banning Santhara – the controversial Jain ritual of fasting unto death. Earlier this month, the high court had ruled that the voluntary religious practice of Santhara was a form of suicide and, therefore, illegal. Jains had protested against the order, saying suicide was sin, whereas Santhara was religion. On Monday, the top court said it would take up the issue for consideration. Legal experts say they expect the case to take several years to come to a conclusion. <http://www.bbc.com/news/world-asia-india-34105602>

Noted in Media Watch, 31 August 2015, #425 (p.8):

- **INDIA** | *The New York Times* – 24 August 2015 – ‘**Sect’s death ritual clashes with Indian law.**’ On a bed in a corner of a sitting room, surrounded by a crowd of reverent visitors, the family’s 92-year-old patriarch, Manikchand Lodha, was fasting to death – an act of Santhara, a voluntary, systematic starvation ritual undertaken every year by several hundred members of the austere, ancient Jain religion. http://www.nytimes.com/2015/08/25/world/asia/sects-death-ritual-raises-constitutional-conflict-in-india.html?_r=0



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.19.

Cancer a major health risk in South Asia

INDIA | *The Times of India* (New Delhi) – 31 August 2015 – Cancer is killing 1 in 10 people in South East Asia region. The World Health Organization (WHO) says “it is a matter of serious concern that 72% of cancer deaths were among those aged below 70 years.” Records show that in 2012, an estimated 1.7 million new cases and 1.2 million deaths occurred due to cancers in the region. WHO projects that by 2030, over 21 million people will be diagnosed and 13 million will die from cancer annually across the globe. WHO South-East Asia Regional Office chief Dr. Poonam Khetrpal Singh told the *Times* in an exclusive interview ... that the ministers will meet in Timor Leste to discuss increasing access to prevention, early detection and treatment of cervical cancer besides technical assistance to establish cancer surveillance and registries in Bhutan, Maldives, Myanmar and Nepal. It will also include capacity-building for palliative care in Indonesia, India and Sri Lanka... The countries will also discuss increasing access to quality and effective pain management and palliative care treatment including access to oral morphine. <http://timesofindia.indiatimes.com/world/south-asia/Cancer-a-major-health-risk-in-South-Asia/articleshow/48748216.cms>

The current status of palliative care in India

CANCER CONTROL, 2015;3:57-62. – Less than 1% of India’s 1.2 billion population has access to palliative care. The efforts by pioneers over the last quarter of a century have resulted in progress, some of which may hold lessons for the rest of the developing world. In recent years, a few of the major barriers have begun to be overcome. The South Indian state of Kerala, which has 3% of India’s population, stands out in terms of achieving coverage of palliative care. This has been achieved initially by non-government charitable activity, which catalyzed the creation of a government palliative care policy. The nongovernment action, by involving the community, serves to strive for quality of care as the government system improves coverage. On the national level, recent years saw several improvements, including the creation of a National Program for Palliative Care by the government of India in 2012. The year 2014 saw the landmark action by the Indian Parliament, which amended India’s infamous Narcotic Drugs & Psychotropic Substances Act, thus overcoming many of the legal barriers to opioid access. Education of professionals and public awareness are now seen to be the greatest needs for improving access to palliative care in India. <http://www.cancercontrol.info/wp-content/uploads/2015/07/57-62-MR-Rajagopal-.pdf>

N.B. *Cancer Control* is published by the International Network for Cancer Treatment & Research.

N.B. India was rated 40th, of 40 countries surveyed, in *The Quality of Death: Ranking End-of-Life Care Across the World*, which was commissioned by The Lien Foundation, of Singapore, and published in the U.K. by the Economist Intelligence Unit, 2010. [Noted in Media Watch, 19 July 2010, #158 (p.3)] http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf



Elder care in Ireland

Additional respite care is needed for ageing population

IRELAND | *The Independent* (Dublin) – 31 August 2015 – The number of people who will reach their mid-60s will rise to almost one million by 2031, according to the National Social Monitor.¹ The document ... says it is anticipating this significant rise in our ageing population, which will represent an 86% increase from our current level. The number of people aged over 85 will also rise to 136,000, an increase of 133%. “Planning to meet this challenge requires a comprehensive approach to care services that would include integrated services across the areas of GP care, public health nursing, home care supports, acute hospital care, rehabilitation and long-term care,” the report details. “Community care and home care support for people to remain in their own homes is a key and appropriate policy objective and coincides with the wishes of most older people. But this commitment does not appear to be supported in practice when we note the significant decrease in the provision of home help hours in recent years, especially at a time of population ageing.” <http://www.independent.ie/irish-news/health/additional-respite-care-is-needed-for-ageing-population-31489468.html>

1. ‘National Social Monitor 2015,’ Social Justice Ireland, “an independent think tank and justice advocacy organisation,” August 2015. <http://www.socialjustice.ie/sites/default/files/attach/publication/3994/2015-08-25-nationalsocialmonitor2015final.pdf>

Dying for right to medical parole

SOUTH AFRICA | *The Sunday Independent* (Johannesburg) – 30 August 2015 – The lack of health care within prisons is an issue that plagues prisons across the country, despite the constitutional requirement that every prisoner is entitled to the exact same health care as what is available at public hospitals. This constitutional requirement is poles apart from reality. Serious over-crowding, staff shortages, and medical neglect seem to exacerbate, sometimes even cause, health problems. In addition, medical parole processes are so cumbersome inmates become increasingly ill, with the threat of death hanging over them, before parole is granted. Several inmates [at Johannesburg Central Prison] have died waiting to be released on medical parole, others die shortly after being released. Some of these deaths could have been avoided had these prisoners been released into family-care, or received better health care behind bars. According to the Department of Correctional Services (DCS), there are 1,469 full-time health care professionals comprising of nurses, medical practitioners, psychologists, pharmacists and social workers to treat 154,648 sentenced and awaiting-trial inmates. South Africa's medical parole regime was overhauled a few years ago, leading to a new administration that came into effect at the end of March 2015. Under the amendments to the Correctional Matters Amendment Act, a Medical Parole Advisory Board was introduced 2012... <http://www.iol.co.za/sundayindependent/dying-for-right-to-medical-parole-1.1907688#.VeRB7s9RGot>

[Prison Hospice Backgrounder](#)

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



Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *Christian Today* – 1 September 2015 – **‘British Protestants are pro euthanasia...’** New analysis [from YouGov.UK] of practising Christians in Britain looks at attitudes to ethical issues among the different faith groups.¹ Overall, the Christian population is more socially Conservative than the country as a whole, but not as much as one might expect. 50% of British Catholics are in favour of same-sex marriage and only 40% are opposed... This is in contrast to the official teaching of the Catholic Church which opposes same-sex marriage and the practice of homosexuality. 59% of British Protestants are in favour of some form of euthanasia for “clearly consenting terminally ill patients,” compared to only 33% who are opposed. Similarly, this is different to the official teaching of the Church of England which is opposed to a change in the law to make any form of euthanasia or assisted dying legal. <http://www.christiantoday.com/article/british.protestants.are.pro.euthanasia.and.catholics.are.pro.same.sex.marriage.yougov.poll.says/63591.htm>

- ‘Catholics for gay marriage; Protestants for euthanasia,’ YouGov UK, September 2015. <https://yougov.co.uk/news/2015/08/27/profile-catholic-protestant-issue/>

[Media Watch: Back Issues](#)

<http://www.ipcrc.net/archive-global-palliative-care-news.php>

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

Concordance of nurses and physicians on whether critical care patients are receiving futile treatment

AMERICAN JOURNAL OF CRITICAL CARE, 2015;24(5):403-410. Exploring the differences in perception of futile treatment between nurses and physicians may provide further information about the various assumptions and bases of the conceptualization of “futile” treatment. We showed that prognostication is improved when physicians and nurses agree on the assessment of futile treatment, which suggests that increased interprofessional collaboration has the potential to improve patient care. Making such assessments explicitly – for instance, by having them stated during interdisciplinary rounds – not only may dispel misperceptions of prognosis (or enhance discussion to clarify differences in perspective), but also foster support for earlier palliation when it is needed. <http://www.aacn.org/wd/Cetests/media/A1524053.pdf>

Paediatric palliative care in the Asia Pacific region: Where are we now?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 3 September 2015 – An online survey was conducted ... among professionals in the region to document current service provision, and at the same time to explore individual training needs and practice challenges. Fifty-nine distinct responses from 16 countries were obtained to build a directory, which has already been circulated. Content analyses of narrative responses yield further findings. Half of these services catered to adults as well as to children. Staffing and service provision varied across the region but most members worked in teams consisting of multidisciplinary professionals. Numerous service and funding models were found, reflecting wide differences in local conditions and responses to diverse patient populations unique to paediatric palliative care. The highest training needs centred around bereavement and spiritual care. Capacity and funding issues were expected, but significant lack of support by paediatricians was found to be alarming and warrants further study. <http://spcare.bmj.com/content/early/2015/09/03/bmjspcare-2014-000812.abstract>



World hospice & palliative care day
10 October 2015

Related:

- *ACTA MÉDICA PORTUGUESA*, 2015;28(4):501-512. ‘**Measuring instruments of the quality of life [in] pediatric palliative care.**’ The most commonly measure dimensions were physical ability, emotional/psychological impact, social and at school impact, followed by pain and discomfort and activity level. The majority of instruments are designed for children aged over 8 years. A large number of the questionnaires are self-completion questionnaires. Others can be completed by parents. Most of the instruments tested their internal coherence and, in a small number, the test-retest reproducibility and agreement among observers. Most of the questionnaires reported their content validity and construct validity, few have examined the validity of criterion. Considering the examined instruments, six questionnaires are validated for the Portuguese population (five generic and one specific for oncologic disease). <http://actamedicaportuguesa.com/revista/index.php/amp/article/view/5395>

N.B. Portuguese language article.

- *PEDIATRIC CRITICAL CARE MEDICINE*, 2015;16(7):e231-e238. ‘**End-of-life practices among tertiary care PICUs in the U.S.: A multicenter study.**’ Most deaths in Collaborative Pediatric Critical Care Research Network–affiliated PICUs occur after life support has been limited or withdrawn. Discussions with families about limitation or withdrawal of support occurred during the initial PICU stay for 173 patients who died. Of these, palliative care was consulted for 67; pain service for 11; and, ethics committee for six. Mode of death was withdrawal of support for 141, failed cardiopulmonary resuscitation for 53, limitation of support for 46, and brain death for 35; mode of death did not differ across sites. http://journals.lww.com/pccmjournal/Abstract/2015/09000/End_of_Life_Practices_Among_Tertiary_Care_PICUs_in.29.aspx

Mandatory disclosure and medical paternalism

ETHICAL THEORY & MORAL PRACTICE | Online – 27 August 2015 – Medical practitioners are duty-bound to tell their patients the truth about their medical conditions, along with the risks and benefits of proposed treatments. Some patients, however, would rather not receive medical information. A recent response to this tension has been to argue that the disclosure of medical information is not optional. As such, patients do not have permission to refuse medical information. The author argues that, depending on the context, the disclosure of medical information can undermine the patient's ability to exercise her autonomy or have therapeutically detrimental effects. In the light of these insights, the author goes on to develop a context-sensitive approach to medical disclosure. The advantage of this account is that it addresses concerns on both sides of the debate; whilst it acknowledges that patients do not have an exercisable "right not to know," it allows that in some cases medical information ought to be withheld. <http://link.springer.com/article/10.1007/s10677-015-9632-2>

Noted in Media Watch, 24 August 2015, #424 (p.16):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 19 August 2015 – '**Does disclosure of terminal prognosis mean losing hope? Insights from exploring patient perspectives on their experience of palliative care consultations.**' This study aimed to elicit seriously ill patients' perspective and experience of an inpatient palliative care consultation, and to explore patient attitudes toward information derived from the consultation. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0038>

Noted in Media Watch, 29 December 2014, #390 (p.9):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 23 December 2014 – '**Discovering the truth beyond the truth.**' Palliative care emphasizes patient autonomy and a patient-centered approach, and it is precisely among patients with chronic, life-threatening, or terminal illnesses that truth plays a particularly crucial role. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00919-1/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00919-1/abstract)

Into the wild country: Epistemic issues in professional guidelines for palliative sedation in end-of-life care

EVIDENCE & POLICY: A JOURNAL OF RESEARCH, DEBATE & PRACTICE, 2015;11(3):331-349. This paper critically examines epistemic issues in professional guidelines for palliative sedation of the dying. As a last resort option, palliative sedation is described as the intentional, pharmacological reduction of the patient's consciousness with the aim to reduce intolerable suffering from intractable physical symptoms that cannot be managed otherwise. Like a wilderness trail that simultaneously facilitates and constrains, the guidelines provide a set of "due care requirements" that allows for the provision of end-of-life care in controversial territory. <http://www.ingentaconnect.com/content/tpp/ep/2015/00000011/00000003/art00003>

Related:

- *JOURNAL OF PALLIATIVE CARE*, 2015;141-149. '**The practice of continuous palliative sedation in long-term care for frail patients with existential suffering.**' Some guidelines ... identify existential suffering as a potential refractory symptom for which continuous palliative sedation (CPS) can be administered under certain conditions. There has been little research on the characteristics of patients with existential suffering treated with CPS and the degree to which the preconditions are fulfilled. <http://search.proquest.com/openview/4d455887ccea4f4b3332540bbaefb083/1?pq-origsite=gscholar>

Noted in Media Watch, 12 May 2014, #357 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – '**Palliative sedation: An analysis of international guidelines and position statements.**' Published guidelines: American College of Physicians-American Society of Internal Medicine (2000), Hospice & Palliative Nurses Association (2003), American Academy of Hospice & Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice & Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). <http://ajh.sagepub.com/content/early/2014/05/06/1049909114533002.abstract>

End-of-life care in Ireland

Cross-border hospice care for youths mooted

THE IRISH MEDICAL TIMES | Online – 31 August 2015 – The Department of Health (DoH) is in consultation with the [Republic of Ireland's] Health Services Executive (HSE) regarding the scope that may exist for cross-border hospice care for children with life-limiting and terminal conditions. New arrangements will have to be agreed by the relevant authorities in Northern Ireland (NI)... Work is continuing within the Ministry [of Health] and the Executive to identify potential opportunities for improving the delivery of health-care through clinical linkages and partnerships on an all-island basis... The Department of Health, Social Services & Public Safety (DHSSPS), in NI has carried out a public consultation on its draft implementation plan for the U.K. Strategy for Rare Diseases published in 2013. The draft plan commits the DHSSPS to identifying opportunities to work with healthcare policy makers, commissioners and providers in the Republic and organisations involved in research in the field of rare diseases to maximise potential benefits arising from collaboration for both jurisdictions. <http://www.imt.ie/news/latest-news/2015/08/cross-border-hospice-care-for-youths-mooted.html>

Noted in Media Watch, 6 April 2015, #404 (p.10):

- *THE MEDICAL INDEPENDENT* (Ireland) | Online – 31 March 2015 – ‘**Call for review of National Children’s Palliative Care Policy.**’¹ A number of leading organisations have jointly called for a review of service delivery priorities ... in light of new figures that show the prevalence of children living with life-limiting conditions is 3,840. The figures are in a letter written on behalf of the Health Services Executive’s National Development Committee for Children’s Palliative Care, in the *Irish Medical Journal*.² <http://www.medicalindependent.ie/62292/call-for-review-of-national-childrens-palliative-care-policy>

1. ‘Palliative Care For Children With Life-Limiting Conditions In Ireland: A National Policy,’ Department of Health & Children, 2010. http://health.gov.ie/wp-content/uploads/2014/03/palliative_care_en.pdf

2. ‘Children with life-limiting conditions: Establishing accurate prevalence figures,’ *Irish Medical Journal*, 2015;108(3). <http://www.imj.ie/ViewArticleDetails.aspx?ArticleID=13977>

The next era of palliative care

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION (JAMA) | Online – 3 September 2015 – In 1995, the pivotal SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment), involving more than 4,000 patients, documented “substantial shortcomings in care for seriously ill hospitalized patients” while demonstrating no improvement in outcomes with a nurse-led communication intervention.¹ These negative results – published in *JAMA* and referenced in more than 1,000 peer-reviewed publications – galvanized efforts to improve advanced illness care. Champions of these efforts became leaders in palliative care – an emerging field focused on improving quality of life and alleviating physical and psychological symptoms for patients with complex serious illness and their families. Initially established as a consult service at a handful of teaching hospitals in the early 1990s, palliative care programs have witnessed substantial expansion over the past two decades.² This growth has been fueled by evidence that specialty palliative care improves outcomes for seriously ill patients and families. In response, professional guidelines now recommend earlier and routine co-management by palliative care specialists. Hospitals are also hiring more palliative care clinicians to staff busy consult services. Yet 20 years after SUPPORT, little has changed for seriously ill patients, who continue to receive poor quality, high-cost care without being informed of likely treatment outcomes so that they would be able to make decisions that reflect their values.³ <http://jama.jamanetwork.com/article.aspx?articleid=2436391>

1. ‘A controlled trial to improve care for seriously ill hospitalized patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT),’ *JAMA*, 1995;274(20): 1591-1598. <http://jama.jamanetwork.com/article.aspx?articleid=391724>

Cont.

2. 'A state-by-state report card on access to palliative care in our nation's hospitals,' Center to Advance Palliative Care and National Palliative Care Research Center,' 2011: <https://www.capc.org>. ['America's care of serious illness: A state-by-state report card on access to palliative care...'] *Journal of Palliative Medicine*, 16 September 2011 was noted in Media Watch, 19 September 2011, #219 (p.9) <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.9634>
3. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>

Hospice palliative care article publications: An analysis of the Web of Science database from 1993 to 2013

JOURNAL OF THE CHINESE MEDICAL ASSOCIATION | Online – 1 September 2015 – Academic publications are important for developing a medical specialty or discipline and improvements of quality of care. As hospice palliative care medicine is a rapidly growing medical specialty in Taiwan, this study aimed to analyze the hospice palliative care-related publications from 1993 through 2013 both worldwide and in Taiwan, by using the Web of Science database. There were a total of 27,788 documents published worldwide during the years 1993 to 2013. The top five most prolific countries/areas with published documents were the U.S. (11,419 documents, 41.09%), England (3,620 documents, 13.03%), Canada (2,428 documents, 8.74%), Germany (1,598 documents, 5.75%), and Australia (1,580 documents, 5.69%). Three hundred and ten documents (1.12%) were published from Taiwan, which ranks second among Asian countries (after Japan, with 594 documents, 2.14%) and 16th in the world. During this 21-year period, the number of hospice palliative care-related article publications increased rapidly. [http://www.icma-online.com/article/S1726-4901\(15\)00208-7/abstract?cc=y=](http://www.icma-online.com/article/S1726-4901(15)00208-7/abstract?cc=y=)

Related:

- *JOURNAL OF PALLIATIVE CARE*, 2015;31(3):133-140. '**Evidence-based palliative care 13 years on: Has anything changed?**' There is a paucity of data on whether interventions in individual palliative care units are evidence based. The authors evaluated the evidence for interventions performed in an inpatient palliative care setting, looking at level of evidence as well as quality and outcome of evidence. More than half of all the interventions (47 interventions, 59%) they looked at in a Brisbane, Australia, in-patient palliative care setting were based on a high level of evidence in the form of systematic reviews of randomized controlled trials (level I or level II). There were only a few interventions (10%) for which no evidence could be retrieved. Results show the evidence base for interventions in palliative care continues to evolve, but that there are still areas for which further high-quality studies are needed. <http://search.proquest.com/openview/4d455887ccea4b6127fde6e347f82e/1?pq-origsite=gscholar>

Noted in Media Watch, 31 August 2015, #425 (p.13):

- *HEALTH INFORMATION & LIBRARIES JOURNAL* | Online – 21 August 2015 – '**How effective are palliative care clinicians in finding the evidence in their field?**' Health professionals must be able to search competently for evidence to support practice. The authors sought to understand how palliative care clinicians construct searches for palliative care literature ... to quantify search efficacy in retrieving a set of relevant articles and to compare performance against a Palliative CareSearch Filter. <http://onlinelibrary.wiley.com/doi/10.1111/hir.12120/abstract>

[Media Watch: Palliative Care Network-e Website](http://www.pcn-e.com/community/pg/file/owner/MediaWatch)

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

“Doctor, make my decisions”: Decision control preferences, advance care planning, and satisfaction with communication among diverse older adults

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 2 September 2015 – Nearly one-fifth of diverse, older adults [i.e., study participants] want doctors to make their medical decisions. Older age and lower readiness to ask questions were the only demographic variables significantly associated with low decision control preferences [DCPs]. Yet, older adults with low DCPs still engaged in advance care planning [ACP], asked questions, and reported communication satisfaction. Clinicians can encourage ACP and questions for all patients, but should assess DCPs to provide the desired amount of decision support. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00446-7/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00446-7/abstract)

Related:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(5):226-231. **‘Exploring the experiences of patients with advanced lung cancer when breaking bad news.’** Professionals receive training and guidelines, but less is known about how patients cope with communicating bad news to family and friends. This study highlighted the difficulties experienced by patients. They require support to communicate with others in an honest and timely fashion; to be able to attend to any unfinished business; and to be able to express their wishes and preferences for future care.

N.B. Access to this article requires a subscription to the journal. Contents page:

http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2015&Edition=545

Palliative care screening and assessment in the emergency department: A systematic review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 31 August 2015 – Emergency Department (ED) providers and policy makers are increasingly interested in developing palliative care (PC) interventions for ED patients. Many patients in the ED may benefit from PC screening and referral. Multiple ED-based PC screening projects have been undertaken, but there has been no study of these projects or their effects. Four studies met inclusion criteria. The authors have identified multiple studies demonstrating that screening and referral for PC consultation is feasible in the ED setting. The strengths and limitations of these studies were explored. Further evidence for the development of an effective, evidence-based PC screening and referral process is needed. They recommend a screening framework based on a synthesis of available evidence. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00444-3/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00444-3/abstract)

Noted in Media Watch, 9 February 2015, #396 (p.11):

- *PALLIATIVE MEDICINE* | Online – 29 January 2015 – **‘What’s in a name? A qualitative exploration of what is understood by “palliative care” in the emergency department.’** There are entrenched contradictions and tensions surrounding the term “palliative care” ... [and] ... confronting these is likely to require more than “re-branding,” and will promote better care for this vulnerable patient group... <http://pmj.sagepub.com/content/early/2015/01/23/0269216314560801.abstract>

Noted in Media Watch, 18 August 2014, #371 (p.12):

- *PALLIATIVE MEDICINE* | Online – 12 August 2014 – **‘What is the incidence of patients with palliative care needs presenting to the emergency department? A critical review.’** Healthcare professionals held contradictory understandings of palliative care (PC) and its application in the emergency department; sub-themes highlighted these inconsistencies when the term “palliative” is used, in understandings of and engagement with PC services, and in perceptions about the practical utility of PC. <http://pmj.sagepub.com/content/early/2014/08/07/0269216314543318.abstract>

Cont.

Noted in Media Watch, 5 August 2013, #317 (p.7):

- *EMERGENCY MEDICINE AUSTRALASIA* | Online – 25 July 2013 – ‘**Do patients die well in your emergency department?**’ Only 49% of survey respondents believed that the emergency department (ED) provided good palliative care (PC), and 80% were unaware of international gold standard PC protocols. Most had access to hospital-based PC specialists (77%); however, only 19% used them. Few undertake any formal training in PC (29%). There is also a need and desire for greater integration of the values and standards of high-quality PC in EDs. <http://onlinelibrary.wiley.com/doi/10.1111/1742-6723.12099/abstract;jsessionid=BF3EB5C23715B5BCDC40C9E6BBA8E026.d04t04?deniedAccessCu stomisedMessage=&userIsAuthenticated=false>

Noted in Media Watch, 4 June 2012, #256 (p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE* | Online – 23 May 2012 – ‘**Why do palliative care patients present to the emergency department? Avoidable or unavoidable?**’ Many emergency department (ED) presentations by palliative care patients may be avoidable. Appropriate sharing of information to on-call doctors, creating confidence in carers, and providing extra practical supports is necessary. A comprehensive, coordinated specialist palliative care approach across community and acute services may help ensure patients are not sent to the ED inappropriately. <http://ajh.sagepub.com/content/early/2012/05/18/1049909112447285.abstract>

Defining a good death: A deliberative democratic view

JOURNAL OF PALLIATIVE CARE, 2015;31(3):158-165. Many attempts to define a good death have been recorded in the academic literature. In most of these attempts, the methods used have been surveys, interviews, and focus groups. These methods have yielded important information, but they have failed to provide an opportunity for public deliberation, whereby people engage collectively with an issue, consider it from all sides, and struggle to understand it. The authors believe that a well-orchestrated public deliberation could contribute to defining a good death. The authors gathered data from four deliberative forums implemented in Finland in November 2013. The results paint a picture that differs from those painted by the previous research, which focused mainly on individual and idealized views of a good death. Their findings have brought to light the messy reality of a good death. Deliberation elicited the concern that society could not provide a good death for all and in the process highlighted the lack of proper palliative care and the dominant role of healthcare professionals in defining a good death. <http://search.proquest.com/openview/903c78b8b8fbbda30a1ac1cc48f7cdf3/1?pq-origsite=gscholar>

Related:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(5):226-231. ‘**Do spiritual beliefs influence coping mechanisms for dealing with death and dying?**’ This study was an attempt to discover common factors in an area that generally presents challenges owing to its sensitive and subjective nature. It has highlighted issues that relate to the metaphysical, spiritual and existential aspects of being human. One of the major themes that emerged is that spirituality provides a positive influence on human coping mechanisms at the end of life. Perhaps more unexpected was the high level of belief, or wish for belief, in a life after death, which motivates participants’ coping strategies. An important factor that came to light ... was the value that people place on having or seeking a life purpose, in connection with spirituality. According to the collected data, many participants had a strong need to contextualise their life with the prospect of a life purpose, in order to cope with the eventuality of death. It could therefore be said that the results evidenced a connection between the belief in a life purpose and end-of-life solace.

N.B. Selected articles on spirituality at the end of life are noted in Media Watch of 17 August 2015, #423 (p.18). Access to *European Journal of Palliative Care* article requires a subscription. Contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2015&Edition=545

Palliative care for a homeless person

NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE | Online – 24 August 2015 – Homeless people have substantial health disadvantages as compared to the general population, and excessive losses in life expectancy. High proportions of psychiatric disorders, substance abuse and intellectual disability have been reported. This makes palliative care for this population extremely complex. A 55-year-old man, addicted to heroin and cocaine, was diagnosed with metastatic lung cancer. His terminal phase of life was complicated by many admissions to different care settings and problems with symptom management. Involvement of a palliative care consultation team and transfer to a homeless shelter, to which homeless people with life-threatening diseases could be admitted, gave both the patient and his family relief. This case illustrates that palliative care in homeless patients may be extremely complex due to the specific physical and psychosocial features involved. <https://www.ntvg.nl/artikelen/palliatieve-zorg-voor-een-dakloze>



N.B. Dutch language article.

Noted in Media Watch, 16 February 2015, #397 (p.10):

- *DEATH STUDIES* | Online – 12 February 2015 – ‘What constitutes a good and bad death? Perspectives of homeless older adults.’ The themes identified for a good death were: 1) Dying peacefully; 2) Not suffering; 3) Experiencing spiritual connection; and, 4) Making amends with significant others. Themes for a bad death were: 1) Experiencing death by accident or violence; 2) Prolonging life with life supports; 3) Becoming dependent while entering a dying trajectory; and, 4) Dying alone. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2014.958629>

N.B. The Summer 2014 issue of *European Network of Homeless Health Worker*, which includes an article on homelessness, ageing and dying (p.7) is available at: http://www.sophie-project.eu/pdf/ENHW_2014.pdf. Selected articles on end-of-life care for the homeless are noted in Media Watch of 3 February 2014, #343 (p.4).

Integrating palliative care into the oncology clinic: A joint management approach

PALLIATIVE MEDICINE | Online – 2 September 2015 – Several international health and cancer organizations, including the American Society of Clinical Oncology,¹ have called for all patients with advanced cancer to have access to palliative care (PC) services. The challenges ... are significant, and ideal approaches to implementation are unclear. Typically, subspecialists practice independently from one another, isolated in separate clinics. For frail cancer patients, this approach is hindered by care coordination confusion, late referrals, and additional burdens of time and travel demonstrated by high no-show rates in PC clinics. In contrast, joint management with a few providers in disease-specific clinics has been successful. <http://pmj.sagepub.com/content/early/2015/09/02/0269216315601947.extract>

1. ‘American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care,’ *Journal of Clinical Oncology*, 6 February 2012 [Noted in Media Watch, 13 February 2012, #240 (p.10)] <http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.abstract>

Related:

- *JAMA ONCOLOGY* | Online – 27 August 2015 – ‘Critical care utilization for those with cancer: How much is enough?’ Intensive care units provide specialized care that can be of high value to those with cancer who experience life-threatening complications of the disease or its treatment. The cost of providing intensive care is high, and unless the societal resources devoted to health care are limitless, we must continually decide how to best allocate resources to those who are likely to benefit. <http://oncology.jamanetwork.com/article.aspx?articleID=2430472>

Cont.

- *LUNG CANCER* | Online – 28 August 2015 – ‘**Integrating early palliative care in the management of lung cancer: The role of the thoracic oncologist.**’ Early introduction of palliative care in the management of patients with metastatic lung cancer is recommended since it improves quality of life and improves survival rates. In many hospitals the focus of palliative teams is often on terminal care due to limited resources. How is early palliative care (EPC) in this setting implemented in daily oncologic care? It seems obvious that thoracic oncologists will have to become involved in EPC for lung cancer patients. In this review the authors want to determine the assignments for the thoracic oncologist in EPC and to give some practical tools how we started EPC in collaboration with the palliative team. [http://www.lungcancerjournal.info/article/S0169-5002\(15\)30040-4/abstract](http://www.lungcancerjournal.info/article/S0169-5002(15)30040-4/abstract)

N.B. Selected articles on the integration of early palliative care with oncology care are noted in Media Watch of 30 March 2015, #403 (pp.15-16) and 22 December 2014, #389 (pp.14-15).

Palliative care in hospital: Why is it so difficult?

PALLIATIVE MEDICINE | Online – 1 September 2015 – We used to trust our hospitals. The original meaning of the word “hospes” relates to guests and hospitality, the same root as hospice and hotel. However, studies tell us hospitals can be the least hospitable of institutions. Shocking reports of hospital complaints in the U.K. relate to care of the dying,¹ suggesting a real deficit of palliative care knowledge and attitudes nearly 50 years after Cicely Saunders established St Christopher’s Hospice ... And why are half of those who die in Europe, America and much of Asia still ending their days in hospital,² when we keep hearing that so many want to spend their last weeks at home? The reasons are many, a toxic mix of culture, ambivalence and expectation. Society remains anxious about death, convinced of immortality and has developed huge expectations about the power of doctors and unlimited medicine. Care of the dying used to be the bread and butter of family doctors – why and where has that confidence gone? At the same time, families are not available or confident to care, community services are fragmented, we do not talk about dying and we do not prepare or plan ahead. The end result of these contextual factors is that thousands of people are admitted to hospital every day, and culture and systems make it very difficult to escape. Studies have suggested that many who are in hospital could be supported elsewhere – however, this depends on citizens, health services and social care working much more cohesively together. <http://pmj.sagepub.com/content/early/2015/08/28/0269216315600996.full>



1. ‘Dying Without Dignity: Investigations by the Parliamentary & Health Service Ombudsman into complaints about end of life care,’ 25 May 2015. [Noted in Media Watch, May 2015, #411 (p.6)] http://www.ombudsman.org.uk/data/assets/pdf_file/0019/32167/Dying_without_dignity_report.pdf
2. ‘Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics,’ *International Journal of Public Health*, 2013;58(2):257-267. [Noted in Media Watch, 17 August 2013, #300 (p.10)] <http://link.springer.com/article/10.1007/s00038-012-0394-5>

Does the use of specialist palliative care services modify the effect of socioeconomic status on place of death? A systematic review

PALLIATIVE MEDICINE | Online – 1 September 2015 – Cancer patients in lower socioeconomic groups are significantly less likely to die at home and experience more barriers to access to palliative care. It is unclear whether receiving palliative care may mediate the effect of socioeconomic status on place of death. Nine studies were included. All study subjects had received specialist palliative care. With regard to place of death, socioeconomic status was found to have 1) no effect in seven studies, and 2) an effect in one study. Furthermore, one study found that the effect of socioeconomic status on place of death was only significant when patients received standard specialist palliative care. When patients received more intense care adapted to their needs, the effect of socioeconomic status on place of death was no longer seen. <http://pmj.sagepub.com/content/early/2015/08/28/0269216315602590.abstract>

Cont.

Noted in Media Watch, 5 March 2012, #243 (p.10):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 29 February 2012 – ‘**Socioeconomic position and place of death of cancer patients.**’ The found socioeconomic differences in whether death occurred at home or at institutions indicate that age, income, and social class must be taken into account when palliative care services engage in fulfilling patient preferences of dying at home. This may lead to more equality in the possibility of dying at home, despite any differences in socioeconomic level. <http://spcare.bmj.com/content/early/2012/02/29/bmjspcare-2011-000116.abstract>

An international comparison of costs of end-of-life care for advanced lung cancer patients using health administrative data

PALLIATIVE MEDICINE | Online – 1 September 2015 – Costs for non-small cell lung cancer patients were slightly higher in the U.S. than in Ontario, Canada... Inpatient hospitalization was the main cost driver with similar costs in both cohorts, despite lower utilization in the U.S. Administrative data allowed exploration and international comparisons of re-imburement policies, health-care delivery, and costs at the end of life. Mean monthly costs increased as death approached were higher in short-term than long-term survivors, and generally higher in the U.S. than in Ontario until the month before death, when they were similar (long-term survivors: US\$10,464 and US\$10,094 ... short-term survivors US\$14,455 and US\$12,836 ... in surveillance, epidemiology and end results – Medicare and Ontario, respectively). <http://pmj.sagepub.com/content/early/2015/08/28/0269216315596505.abstract>

Related:

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 31 August 2015 – ‘**Racial/ethnic differences in inpatient palliative care consultation for patients with advanced cancer.**’ Inpatient settings may neutralize some racial/ethnic differences in access to hospice and palliative care services; irrespective of race/ethnicity, rates of inpatient palliative care consultation remain low and occur close to death. <http://jco.ascopubs.org/content/early/2015/08/31/JCO.2015.61.6458.abstract?sid=12effbd7-17f4-4f3f-b825-0e442c949365>

Unmet supportive cancer care needs: An exploratory quantitative study in rural Australia

WORLD JOURNAL OF ONCOLOGY, 2015;6(4):387-393. This study, the first in rural Australia, has identified areas in supportive care in which the patients with advanced incurable types of cancer have unmet needs. Further, the study has shown that research on developing strategies to deal with cancer related fatigue, and improvements in psycho-social supports, especially in remote areas will serve the purpose of helping advanced cancer patients. The study has also brought to light that there should be greater emphasis to include psycho-social outcome measures in oncology trials and the idea of “personalized cancer therapy” should be broadened encompassing physical, psychological and social aspects of cancer care. Imparting the unmet care needs of patients to the healthcare professionals periodically by training initiatives will enable them to inform the patients on the existing care services available and also give scope for the patients to conceive and communicate their own priorities on supportive care against the backdrop of indefinite treatment outcomes, thus, bridging the care-management gaps in cancer care. <http://wjon.org/index.php/wjon/article/view/928/667>



Noted in Media Watch, 13 May 2013, #305 (p.16):

- *RURAL & REMOTE HEALTH* | Online – 8 May 2013 – ‘**Considering Aboriginal palliative care models: The challenges for mainstream services.**’ Aboriginal people in Australia account for a small proportion of the population, have poorer health outcomes, and their culture demonstrates a clear resistance to accessing mainstream health services which are viewed as powerful, isolating and not relevant to their culture, way of life, family and belief systems. Aboriginal people tend to not access palliative care services ... and there is very little data on Aboriginal admissions to palliative care centres. Over the last two decades only two models of palliative care focusing on and developed in Aboriginal communities have been implemented. <http://www.rrh.org.au/articles/subviewaust.asp?ArticleID=2339>

Worth Repeating

Palliative care for families: Remembering the hidden patients

CANADIAN JOURNAL OF PSYCHIATRY, 2004; 49(6):359-365. Families of patients receiving palliative care are profoundly affected by the challenges of the illness. They observe care that the patient receives, provide care for the patient, and receive support from health professionals in the form of information, counselling or practical assistance. As they witness and participate in the patient's care, they judge the quality of care that the patient receives. They often see themselves as the patient's care advocates and may harbour regret and guilt if they believe the patient did not have the best possible care. The illness experience profoundly affects family members' psychological and physical health; recognition of this has coined the term "hidden patients." This article briefly synthesizes empirical work that suggests how to best support families... The authors discuss how to define the family, emphasizing a systems approach to family care. They describe the impact of the illness on the family in terms of family members' health, family communication issues, psychological issues, needs for information, physical care demands, and family costs of caring. <https://ww1.cpaapc.org/Publications/Archives/CJP/2004/june/kristjanson.pdf>



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.

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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.

Media Watch: Online

International

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

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

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

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

Asia

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

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

Australia

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

Canada

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

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

Europe

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

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

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

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