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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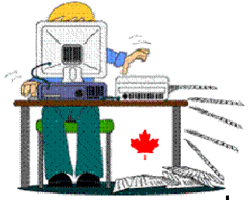

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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'Between worlds: The experiences and needs of former family carers' (p.11), in *Health & Social Care in the Community*.

Canada

Judge says forcing aboriginal girl to stay in chemo is to "impose our world view on First Nation culture"

ONTARIO | *The National Post* – 16 October 2014 – For Laurie Hill, resident of Canada's largest aboriginal community, it's just wrong to suggest that modern medicine is the only way to treat cancer and other serious diseases. She stands firmly behind the Six Nations neighbours who took their 11-year-old daughter with leukemia out of chemotherapy, and are treating her with traditional, but unproven, native methods and other alternative health-care instead. "There's a fear of [aboriginal remedies] or denial of it. If things can't be quantified or qualified, to them it's irrelevant," said Ms. Hill... "Who are they [doctors] to say she will make it with their treatments. Just because they have a degree, that makes them more knowledgeable? Her perspective on what seems to be a widening cultural divide received some recognition from a surprising quarter Thursday: the judge deciding whether the cancer-stricken girl should be forced back into chemotherapy. As an extraordinary court case ... moved toward an end, a lawyer for McMaster Children's Hospital argued that child-welfare authorities should have used their power to require the young woman to stay in treatment. With chemo, childhood leukemia now has a survival rate in the range of 90%, and remains a likely death sentence without it, experts say. But Justice Gethin Edward of the Ontario Court of Justice suggested physicians essentially want to "impose our world view on First Nation culture." The idea of a cancer treatment being judged on the basis of statistics that quantify patients' five-year survival rate is "completely foreign" to aboriginal ways, he said. http://news.nationalpost.com/2014/10/16/judge-says-forcing-aboriginal-girl-to-stay-in-chemo-is-to-impose-our-world-view-on-first-nation-culture/

Extract from *The National Post* report

[Ontario's] Health Care Consent Act allows a patient of any age to potentially be capable of agreeing, or not, to treatment. In this case, though, it was clear to doctors that the girl was a typical 11-year-old and not sophisticated enough to make such a life-and-death decision.

Death determination debate rages on in science, medicine

CBC NEWS | Online – 14 October 2014 – It's not always easy to determine if someone is dead. Science, medicine, law or religions don't always offer simple guidance either. But specific details around death do matter, and are not merely topics for philosophical debate. For example, when should someone be taken off life support? When is someone dead enough for organ donation? The difficult topic of death will be at the forefront in Ottawa this week as the Supreme Court of Canada hears arguments in a case that could make medically assisted death legal on a federal level. That court action is hardly the only legal focus on medical and ethical questions that can arise around death. http://www.cbc.ca/news/technology/death-determination-debate-rages-on-in-science-medicine-1.2795784

Noted in Media Watch, 22 September 2014, #376 (p.11):

- *JOURNAL OF CLINICAL ETHICS*, 2014;25(3):245-257. **'Brain death and total brain failure.'** The author categorizes recent legal developments [as follows]: 1) history of determining death by neurological criteria; 2) legal status of determining death by neurological criteria; 3) legal duties to accommodate family objections; 4) protocols for determining death by neurological criteria; 5) court cases seeking physiological support after DDNC [death determined by neurological criteria]; 6) court cases seeking damages for intentionally premature DDNC; 7) court cases seeking damages for negligently premature DDNC; 8) court cases seeking damages for emotional distress; and, 9) pregnancy Limitations on DDNC. http://www.clinicalethics.com/

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online – 13 October 2014 – **'Assisted suicide: Where do Canada and other countries stand?'** The debate on medically assisted death will be front and centre again ... as the Supreme Court of Canada hears arguments ... in a case that could make the practice legal on a federal level mere months after Quebec adopted its own law allowing it. The constitutional challenge of the Criminal Code prohibition on assisted suicide was launched on behalf of two B.C. patients who have both since died. The court will have to decide whether the law violates Sections 7 and 15 of the Charter of Rights & Freedoms. The first guarantees the right to life, liberty and security of a person, and the second ensures equal treatment before the law for all – which right-to-die advocates have argued is violated when people who are physical disabled are not able to take their own life as able-bodied individuals are. A decision is not expected for months, but right-to-die advocates say the time could be right for Canada's highest court to overturn the law given recent polls suggesting there is broad public support for legalization of assisted suicide. We take a look at where legislation stands today, in Canada and abroad. http://www.cbc.ca/news/canada/assisted-suicide-where-do-canada-and-other-countries-stand-1.2795041

  Sample of reader/viewer *et al* comments/feedback following the Supreme Court of Canada hearing:

  - *THE GLOBE & MAIL* | Online – 15 October 2014 – **'Talking Point – the right to a physician-assisted death – and letters to the editor.'** Like Canada's top justices, readers, print and digital, held court this week on whether the terminally ill and suffering should have the right to a physician-assisted death. http://www.theglobeandmail.com/globe-debate/letters/oct-18-this-weeks-talking-point-the-right-to-a-physician-assisted-death-and-letters-to-the-editor/article21144362/
  - CBC NEWS | Online – 15 October 2014 – **'Doctor-assisted suicide sparks debate amongst CBC readers.'** When can an individual who is suffering choose to end his or her own life? Should they have that choice? Who makes that decision? Readers are divided on the issue. http://www.cbc.ca/newsblogs/yourcommunity/2014/10/doctor-assisted-suicide-sparks-debate-amongst-cbc-readers.html

  N.B. The Supreme Court of Canada's decision is not expected for several months.

U.S.A.

Arizona tests popularity of the dying's right to try unapproved drugs

ARIZONA | *Governing* – 16 October 2014 – The state is the first to let voters decide whether to make experimental drugs available to terminally ill patients – a growing movement that started in a few state legislatures this year. Advocates argue that dying patients can't wait on Federal Drug Administration (FDA) clinical trials that can take a decade, and existing programs to allow patients to obtain unapproved drugs are still too slow for someone with little time left. The [existing] laws allow for access to unapproved drugs, but with some caveats. The drug must have passed initial toxicity and dosage testing under the FDA's clinical trial process. Doctors also can't prescribe an unapproved drug unless the patient has exhausted other options. Manufacturers are under no obligation to provide the drugs and insurers aren't required to pay for them. While the laws have received bi-partisan support in state legislatures, they're not without detractors. http://www.governing.com/topics/elections/gov-arizona-ballot-measure-experimental-drugs.html

Noted in Media Watch, 6 October 2014, #378 (p.11):

- *JAMA INTERNAL MEDICINE* | Online – 29 September 2014 – **'The strange allure of state "right-to-try" laws.'** State "right-to-try" laws that purport to allow patients to be treated with unapproved drugs or devices seem likely to be futile. In May 2014, the governor of Colorado signed into law a so-called right-to-try bill; the intent of the law is to allow terminally ill patients to receive treatment outside of clinical trials with drugs and medical devices that the FDA has not approved for marketing. http://archinte.jamanetwork.com/article.aspx?articleid=1910562

The end-of-life battle over Jewish souls

NEW YORK | *Forward* – 15 October 2014 – Many Orthodox Jews, particularly ultra-Orthodox Jews, believe that as long as the heart beats, the soul is alive. For such Jews, withdrawing life support is akin to murder. Rabbi Shmuel Lefkowitz, vice president of community services at Agudath Israel of America, an ultra-Orthodox group, said that a few years ago his organization received a spate of calls from families complaining about doctors who wanted to remove brain-dead patients from life support. During the same period, Lefkowitz said that Agudath Israel also became concerned about pending legislation in New York State that required doctors to discuss palliative care options with terminally ill patients. The bill's authors believed that the Palliative Care Information Act would ensure that patients were offered the option of a more dignified, less painful death. But in Agudath Israel's eyes, the bill was one more step in society's march toward helping people to die instead of treating them. http://forward.com/articles/207121/the-end-of-life-battle-over-jewish-souls/?p=all

Of related interest:

- NEW YORK | *Forward* – 15 October 2014 – **'How are we to die?'** The decision over whether to enter hospice elevates the wrenching question of how to die to a more complex level. This is especially so for 21st-century Americans accustomed to going the distance, whatever the likelihood of success, and for a medical establishment incentivized to do what it takes – the *clichés* are all apt here – and for Jews obliged to treat every moment of life as sacred. http://forward.com/articles/207167/how-are-we-to-die/

Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.14.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE ECONOMIST* | Online – 16 October 2014 – **'Seizing some control.'** Assisted suicide has been legal in a few European countries for years. But progress in America has been halting: in 1997 the Supreme Court unanimously ruled that the constitution does not include the right to suicide. Aid-in-dying has ideological affinities with other issues where personal autonomy and liberty are at stake – same-sex marriage, for instance, or a woman's right to an abortion. Yet many Americans have long been uncomfortable with sanctioning suicide. This seems to be changing. Now more than two-thirds of Americans support aid-in-dying laws for the terminally ill and mentally competent. Death with dignity legislation is now pending in seven states. But why have Americans held out for so long? And what has changed now? A guaranteed right to an easeful death is a complex matter, made trickier still by religious doctrine. http://www.economist.com/blogs/democracyinamerica/2014/10/right-die

International

How Irish people want to die

IRELAND | *The Irish Times* (Dublin) – 18 October 2014 – Four hundred thousand people have already died in Ireland since the start of the century, an average of eighty a day. Yet how much do we know of the experience of dying? How many achieve that seemingly oxymoronic end ardently prayed for by older generations: a happy death? In their darkest hour, for example, do they have night nurses radiating competence and reassurance of a kind that allows the dying person and loved ones to focus on the sacred journey instead of fearing the physical process ? And do they know that the nurses who bring those incomparable blessings are funded entirely by charity? This is one of the startling discoveries in a conversation with the chief executive of the Irish Hospice Foundation (IHF), Sharon Foley, about the end-of-life process in a country that famously regards all life as sacred. It's a crucial point, as, in a new Foundation survey, three out of every four people surveyed about their end-of-life wishes said they would like to die at home.[1] Although the figure is well up on 10 years ago, the reality remains that only four in 10 do so. http://www.irishtimes.com/life-and-style/how-irish-people-want-to-die-1.1967713

1. 'Irish Attitudes to Death, Dying & Bereavement,' Irish Hospice Foundation, October 2014. http://hospicefoundation.ie/wp-content/uploads/2014/10/Weafer-J-2014-Irish-attidudes-to-death-dying-bereavement-2004-2014.pdf

Key recommendations on cancer plan for Wales

U.K. (Wales) | ITV News (Cardiff) – 16 October 2014 – The National Assembly for Wales's Health & Social Care Committee has issued 13 recommendations to help ensure the Welsh Government's Cancer Plan is delivered as planned, i.e., "That the Minister for Health & Social Services sets out the actions which will be taken ... to reduce inequities in access to end-of-life and palliative care, and provides the Committee with an update after 12 months on the impact of those actions." http://www.itv.com/news/wales/update/2014-10-16/key-recommendations-on-cancer-plan-for-wales/

Noted in Media Watch, 25 August 2014, #372 (p.7):

- U.K. (Wales) | ITV News (Cardiff) – 18 August 2014 – **'£6.4 million of funding for specialist end-of-life care.'** The new funding for hospices and health boards will ensure specialist consultant, nurse and other health support for palliative care is available in all parts of the country. http://www.itv.com/news/wales/update/2014-08-18/6-4-million-of-funding-for-specialist-end-of-life-care/

End-of-life care in England

Dying at home patients "lack 24-hour expert support"

U.K. (England) | BBC News – 15 October 2014 – The National Health Service [NHS] is failing to provide access to 24-hour support for the majority of patients dying at home in England, according to health charity Sue Ryder. Around 92% of NHS clinical commissioning groups (CCGs) do not provide round-the-clock telephone help lines. Guidelines say there should be 24-hour telephone services...[1] The charity asked all 211 CCGs in England whether they had commissioned 24-hour end-of-life care support, including help lines staffed by nurses. Out of 180 CCGs which responded to requests for information from the charity, only 8% said their local area had a dedicated 24-hour help line and palliative care coordination centre. http://www.bbc.com/news/health-29612283

Extract from BBC report

Sue Ryder said there is an "obvious inequality" between help and advice for the start and the end of life, with 24-hour, seven-day-per-week help available for maternity issues.

Specialist Publications

'I never knew that! Why do people from Black and Asian minority ethnic groups in Leicester access hospice services less than other groups? A discussion with community groups,' (p.11), in *Diversity & Equality in Health & Care*.

1. 'One chance to get it right: Improving people's experience of care in the last few days and hours of life,' Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.7)] https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations

Noted in Media Watch, 15 September 2014, #375 (p.5):

- U.K. (England) | Press Association – 12 September 2014 – **'Many boards "ignore needs of dying."'** The needs of dying people and their families are being "ignored" by many local health bodies, charities warned.[1] Just over four in 10 Health & Wellbeing Boards in England consider the needs of people nearing the end of their lives, according to Help the Hospices and the National Council for Palliative Care. http://www.ncpc.org.uk/news/hwb-report

    1. 'Mapping England's Health & Wellbeing Boards' vision of dying people,' Help the Hospices (recently re-named Hospice UK) and the National Council for Palliative Care, September 2014. http://www.ncpc.org.uk/sites/default/files/HWBs_Report.pdf

End-of-life care in Taiwan

Easing the pain over matters of life and death

TAIWAN | *The Strait Times* – 13 October 2014 – In Taiwan, people from all walks of life … voluntarily attend sessions to learn how to care for terminally ill patients. High school students also attend classes as part of their curriculum to learn about the dignity of life and death. The comfort level of the … Taiwanese public in dealing with the often-taboo topic of death is one reason that Taiwan was ranked top in Asia in the 2010 Quality of Death Index produced by the Economist Intelligence Unit.[1] http://yourhealth.asiaone.com/content/easing-pain-over-matters-life-and-death

1. *The Quality of Death: Ranking End of-life-care Across the World*, Economist Intelligence Unit, July 2010. Commissioned by the Lien Foundation, Singapore. [Noted in Media Watch, 19 July 2010, #158 (p.3)] http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

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

Inspectors found "do not resuscitate" forms completed inconsistently at hospital

U.K. (Scotland) | *The Evening Times* (Glasgow) – 13 October 2014 – The Healthcare Improvement Scotland inspectors noted issues with the documentation when they visited Inverclyde Royal Hospital... They have asked National Health Service Greater Glasgow & Clyde … to make improvements in 14 areas following the report, which the health board must address "as a matter of priority." The visit was part of the programme of inspections on the standard of care for older people in acute care. During their visit the inspectors examined "do not attempt cardiopulmonary resuscitation" … documentation... Sometimes medical staff will decide not to try and resuscitate a patient, and may decide not to share this information as they feel it may cause too much distress for the patient and their families. Three of the eight forms … reviewed did not document whether the decision had been discussed with the patient or relatives, meaning they could not be sure the patient or their relatives were aware of the decision. http://www.eveningtimes.co.uk/news/u/inspectors-found-do-not-resuscitate-forms-completed-inconsistently-at-hospital.1413201956

Specialist Publications

'Experience with a hospital policy on not offering cardiopulmonary resuscitation when believed more harmful than beneficial' (p.12), in *Journal of Critical Care.*

Noted in Media Watch, 13 October 2014, #379 (p.11):

- BRITISH MEDICAL ASSOCIATION, (U.K.) RESUSCITATION COUNCIL & THE ROYAL COLLEGE OF NURSING | Online – Accessed 8 October 2014 – **'Decisions relating to cardiopulmonary resuscitation.'** This new edition takes into account developments in clinical practice and developments in the law regarding anticipatory decisions about cardiopulmonary resuscitation. The guidance identifies key ethical and legal principles that should inform all CPR decisions. https://www.resus.org.uk/pages/DecisionsRelatingToCPR.pdf

End-of-life care in Australia

Hospice option for Orange to be considered as palliative care discussed

AUSTRALIA (New South Wales) | ABC News – 12 October 2014 – A hospice for the dying has been proposed as an option for Orange's palliative care needs. There's been a lot of debate among local and state politicians and health workers about what is currently available in Orange after claims of inadequate and inappropriate care for the dying. Last week Orange City Council passed a motion ... to start a petition to the state government calling for improved resourcing and the re-opening of the medical ward previously used for palliative care at the Orange Health Service. The council resolved to write to the Orange Health Service raising concerns about the level of support for palliative care at the hospital and to urge it to establish a ... fund to allow for community donations specifically directed to palliative care. http://www.abc.net.au/news/2014-10-13/hospice-option-for-orange-to-be-considered-as-palliative-care-d/5806662

Palliative care think tank: Council to examine all models before making decision

AUSTRALIA (New South Wales) | *Central West Daily News* (Orange) – 15 October 2014 – Palliative care models in other areas will be examined before Orange City Council decides a course... http://www.centralwesterndaily.com.au/story/2624720/palliative-care-think-tank-council-to-examine-all-models-before-making-decision/?cs=103

Cont.

Noted in Media Watch, 1 September 2014, #373 (p.5):

- AUSTRALIA (New South Wales) | Agency for Clinical Investigation Palliative Care Network – **'Palliative & End-of-Life Care: A Blueprint for Improvement.'** – September 2014 – This report ... emphasises the need for an integrated approach to care whereby relationships between specialist palliative care providers and care providers across all settings of care are fostered. http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0007/240100/progress-report-palliative-and-end-of-life-care-a-blueprint-for-improvement.pdf

End-of-life care in India

Only one per cent of needy get palliative care

INDIA (Kerala) | *The Deccan Chronicle* (Thiruvananthapuram) – 12 October 2014 – Palliative care activist Dr. M.R. Rajagopal has said that only about one percent of the needy have access to palliative care in India. Of the 80 lakh patients who die every year, at least 50 lakh need palliative care, said Dr. Rajagopal... The major reasons for the absence of palliative care are lack of awareness, lack of palliative care education to doctors and nurses, and lack of access to affordable essential medicines, including morphine. In its ten years of existence, Pallium India ... has established ten palliative care centres in north and nine in north-eastern states where there was none before... Pallium India also ran eleven community-based link centres in Thiruvananthapuram district. Trivandrum Institute of Palliative Sciences is a WHO-collaborating centre ... [and] ... has trained 140 doctors, 120 nurses and 35 allied health care professionals, and more than 900 volunteers. http://www.deccanchronicle.com/141012/nation-current-affairs/article/world-palliative-care-day-only-cen-needy-get-palliative-care

N.B. A lakh is a unit in the South Asian numbering system equal to one hundred thousand.

Selected articles on end-of-life care in India noted in past issues of Media Watch:

- *INDIAN JOURNAL OF CRITICAL CARE MEDICINE*, 2014;18(9):615-635. **'End-of-life care policy: An integrated care plan for the dying.'** The Indian Society of Critical Care Medicine published its first guidelines on end-of-life care in 2005, which was later revised (2012). [Noted in Media Watch, 15 September 2014, #375 (p.12)] http://ijccm.org/article.asp?issn=0972-5229;year=2014;volume=18;issue=9;spage=615;epage=635;aulast=Myatra

- *INDIAN JOURNAL OF PALLIATIVE CARE*, 2014;20(3):171-181. **'End of life care policy for the dying: Consensus position statement of Indian Association of Palliative Care.'** End-of-life care in India is delivered ineffectively, with a majority of the Indian population dying with no access to palliative care at end of life and essential medications for pain and symptom control. This position paper is an effort to achieve ... a nationwide, uniform policy... [Noted in Media Watch, 11 August 2014, #370 (p.11)] http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2014;volume=20;issue=3;spage=171;epage=181;aulast=Macaden

- HUMAN RIGHTS WATCH | *World Report 2014* – 23 January 2014 – **'Palliative care: International perspective.'** After a series of positive steps in 2012 ... progress on palliative care in India slowed considerably in 2013. The government has so far not allocated a budget to implement India's progressive national palliative care strategy and parliament failed to consider critical amendments to the Narcotic Drugs & Psychotropic Substances Act [1985] that would dramatically improve the availability of strong pain medications. [Noted in Media Watch, 27 January 2014, #342 (p.6)] http://www.hrw.org/sites/default/files/wr2014_web_0.pdf

Media Watch posted on Palliative Care Network-e Website

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

A point of view: How do we give dignity to the dying?

U.K. | BBC News Magazine – 12 October 2014 – We do much better with the start of life than people ever have before – infant and mother mortality both show this ... [and] ... we still do much better with children than people mostly have in the past – hovering over-attentively around them being a small sin compared to beating them and sending them out into the fields and mines and factories. The middle of life, frankly, we seem to do about as badly or as well as the last centuries did... But with the end of life we do very badly – I won't say worse, because it was never good, but with more indignity and casual cruelty than once attended on the rituals of dying. Trying to define what it is that is so obviously and painfully missing from the way we die now, we all land on that one word "dignity" and struggle to articulate what it means and how and why it's missing. http://www.bbc.com/news/magazine-29565968

Breast cancer victims "left in needless pain": Terminally ill failed by care system

U.K. (England) | *The Daily Mail* – 12 October 2014 – Women with incurable breast cancer are needlessly suffering pain in their last months of life. Some are left in agony for years even though treatments are available, Breast Cancer Care has warned. Its poll of more than 200 women with incurable cancer found 90% were often in pain. More than half suffered every day. If the results are mirrored across all breast cancer patients, more than 32,000 women will be affected. Dr. Emma Pennery, Breast Cancer Care's clinical director, said although pain cannot be eliminated in all cases, prompt referral to a specialist boosts the odds of relief. But she said pain relief may be overlooked because doctors are so focused on treating the cancer. http://www.dailymail.co.uk/health/article-2790374/breast-cancer-victims-left-needless-pain-terminally-ill-failed-care-system.html

Extract from *The Daily Mail* report

Some medics also wrongly associate palliative care – the management of symptoms and pain – only with the very end of life, but help can be given much earlier. But as many as 41% of those polled had never been offered palliative care.

Elder care in the U.K.

National Health Service patients "frightened to complain about poor treatment" because they fear they'll be branded troublemakers, watchdog finds

U.K. (England) | *The Daily Mail* – 12 October 2014 – Most patients are scared to complain about poor treatment because they fear that they will be "branded troublemakers" by the NHS [National Health Service]. Some are even denied treatment after raising concerns, the new patients' watchdog Healthwatch England has found, while others are labelled "serial complainers." Despite concerted efforts to make the NHS more open when things go wrong, Healthwatch has discovered that a pervasive "culture of fear" means many patients are still petrified to make complaints. The watchdog, which is the official voice of the patient in the NHS and social care, will present a 50-page report to Parliament this week outlining its concerns and setting out a series of recommendations.[1] http://www.dailymail.co.uk/news/article-2789637/nhs-patients-frightened-complain-poor-treatment-fear-ll-branded-troublemakers-watchdog-finds.html

1. 'Suffering in silence: Listening to consumer experiences of the health and social care complaints system,' a Healthwatch England Report, October 2014. See 'Jennifer's experience...' (p.21). http://www.healthwatch.co.uk/sites/default/files/hwe-complaints-report.pdf

Only one in 12 Moldovans with incurable diseases enjoy palliative care

MOLDOVA | Info-Prim-Neo (Chişinău) – 11 October 2014 – In Moldova, only one in 12 persons suffering from incurable diseases are given palliative care. About 25,000 people, including over 1,500 children, need such care annually. Moldova integrated palliative care into the health system in 2010, when a series of services started to be funded with public money. However, the limited access to palliation services and pain medication and insufficient public funding are the most serious challenges faced by this sector. In order to improve access to palliative care, the National Association of Palliative Care submitted a national palliative care program to the Ministry of Health... In Moldova, there are 20,000 people involved in giving palliative care – about 50 professionals, 100 volunteers, and over 19,000 caregivers. http://www.ipn.md/en/societate/65053

Assisted (or facilitated) death

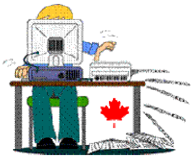
Representative sample of recent news media coverage:

- GERMANY | Deutsche Welle – 16 October 2014 – **'German parliament discusses euthanasia for terminally ill patients.'** A group of prominent German MPs have listed a set of requirements to legalize assisted suicide in the country ... [and] ... a German court also ruled in favor of a coma patient's decision to forgo life-support treatment. http://www.dw.de/german-parliament-discusses-euthanasia-for-terminally-ill-patients/a-18000591

- U.K. (England & Wales) | *The Daily Telegraph* – 16 October 2014 – **'Assisted suicide guidelines relaxed by Director of Public Prosecutions.'** Doctors and nurses who help severely disabled or terminally ill people to take their own lives are less likely to face criminal charges after Britain's most senior prosecutor amended guidelines on assisted suicide. Until now all health care professionals faced a greater chance than others of being prosecuted for helping people to die because of the trust their patients placed in them. Alison Saunders, the Director of Public Prosecutions, said this special deterrent would now only apply to those directly involved in a person's care. http://www.telegraph.co.uk/health/11168519/Assisted-suicide-guidelines-relaxed-by-Director-of-Public-Prosecutions.html

- U.K. (England) | *The Daily Telegraph* – 15 October 20 14 – **'Assisted dying: More than 300 terminally ill people a year committing suicide.'** More than 300 terminally ill people in England a year could be taking their own lives because there is no possibility of assisted suicide, a new study claims. Figures disclosed under the Freedom of Information Act show that just over seven per cent of suicides over the past five years involved people with a terminal illness. http://www.telegraph.co.uk/news/uknews/assisted-dying/11163992/Assisted-dying-more-than-300-terminally-ill-people-a-year-committing-suicide.html

- INDIA | *The Times of India* – 12 October 2014 – **'End of life distinct from euthanasia, experts say.'** The Indian Society of Critical Care Medicine and Indian Association of Palliative Care ... clarified end of life was distinct from "euthanasia" and the two terms should not be confused. Both the organizations also joined hands to campaign for what they call a "good death." In the healthcare sector, critical care is usually associated with curing acute conditions and palliative care is often seen as just the opposite. http://timesofindia.indiatimes.com/india/End-of-life-distinct-from-euthanasia-experts-say/articleshow/44788272.cms



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

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

Identifying patients in the acute psychiatric hospital who may benefit from a palliative care approach

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 15 October 2014 – Criteria are established that identify hospitalized medical patients who are near end of life, yet there are no criteria with respect to hospitalized patients with psychiatric disorders. 22% of patients [i.e., study participants] met National Hospice & Palliative Care Organization non-cancer criteria for dementia. Palliative care intervention should be considered when treating in-patients with psychiatric disorders, especially older patients who have a previous hospitalization or history of dementia. http://ajh.sagepub.com/content/early/2014/10/13/1049909114554795.abstract

Of related interest:

- *PRIMARY CARE COMPANION FOR CNS* [Central Nervous System] *DISORDERS*, 2014; 16(3). **'The integration of palliative care into medical care.'** Working as part of a palliative care medical team for a number of years has provided a continuing exposure to the landscape of medicine. Some elements of health care have changed. For example, the number of consultations to our team has increased. Some elements of training in health care, however, have remained the same. Some physicians think of palliative care only when their patients reach the end of life. This concept represents a loss for the patient and for his or her family as well. http://www.psychiatrist.com/pcc/article/Pages/2014/v16n03/14f01670.aspx

A qualitative study of unmet healthcare needs in chronic obstructive pulmonary disease: A potential role for specialist palliative care?

ANNALS OF THE AMERICAN THORACIC SOCIETY | Online – 10 October 2014 – Patients with chronic obstructive pulmonary disease (COPD) have high symptom burdens and poor health related quality of life. The American Thoracic Society issued a consensus statement outlining the need for palliative care for patients with chronic respiratory diseases.[1] A better understanding of the unmet healthcare needs among patients with COPD may help determine which aspects of palliative care are most beneficial. Six themes were identified [in this study]. (1) Understanding of disease: Most participants correctly identified their diagnosis and recognized their symptoms worsening over time. Only half understood their disease severity and prognosis. (2) Symptoms: Breathlessness was universal and severe. (3) Physical limitations: COPD prevented participation in activities. (4) Emotional distress: Depressive symptoms and/or anxiety were present in most participants. (5) Social isolation: Most participants identified social limitations and felt confined to their homes. (6) Concerns about the future: Half of participants expressed fear about their future. http://www.atsjournals.org/doi/abs/10.1513/AnnalsATS.201404-155BC#.VD0FQ7DF_YQ

1. 'An Official American Thoracic Society Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses' [March 2007], published in the *American Journal of Respiratory & Critical Care Medicine*, 2008;177(8):912-927. http://www.thoracic.org/statements/resources/hcpeeolc/palliative-care.pdf

Selected articles on palliative care for patients living with chronic obstructive pulmonary disease noted in past issues of Media Watch:

- *RESPIRATORY MEDICINE* | Online – 27 June 2013 – **'Referral to palliative care in COPD and other chronic diseases: A population-based study.'** Patients with COPD [i.e., study participants] (20%) were less likely than those with heart failure (34%), severe dementia (37%) or cancer (60%) to be referred to palliative care services. [Noted in Media Watch, 8 July 2013, #313 (p.11)] http://www.sciencedirect.com/science/article/pii/S0954611113002151

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- *EUROPEAN RESPIRATORY REVIEW*, 2012;21(126):347-354. **'Palliative care in COPD patients: Is it only an end-of-life issue?'** The presence of acute or chronic respiratory failure is often seen as a terminal phase of chronic obstructive pulmonary disease. A great variability in end-of-life practice is observed in these patients mainly because physicians are not always able to correctly predict survival. [Noted in Media Watch, 10 December 2012, #283 (pp.9-10)] http://err.ersjournals.com/content/21/126/347.abstract

Of related interest:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 15 October 2014 – **'"The unpredictable death" – The last year of life for patients with advanced COPD: Relatives' stories.'** All relatives [i.e., study participants] described the patients as having had a peaceful death that did not correspond with the worry expressed earlier by both the patients and themselves. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9384384&fulltextType=RA&fileId=S1478951514001151

Music therapy in children's hospices: An evaluative survey of provision

THE ARTS IN PSYCHOTHERAPY | Online – 13 October 2014 – Music therapists are challenged to work with children with life-limiting and life-threatening conditions during short periods of respite care over several years or at end of life. Flexibility is fundamental to working both individually and in small groups in response to the shifting needs of the children and their families. In the context of a children's hospice music therapists are called upon to work creatively with siblings and family members and members of the multidisciplinary team in addition to the children themselves. http://www.sciencedirect.com/science/article/pii/S0197455614001051

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

I never knew that! Why do people from Black and Asian minority ethnic groups in Leicester access hospice services less than other groups? A discussion with community groups

DIVERSITY & EQUALITY IN HEALTH & CARE, 2014;11(3-4):237-245. In the U.K., Black & Asian Minority Ethnic (BAME) patients are less likely to access palliative care services than their White counterparts. An increasingly diverse population makes this a cause for concern. This paper describes a project ... to discover what members of the BAME communities knew about palliative care and the providers of hospice services; what they thought the barriers were to their use of these services; and, how they would like to find out about them. Findings suggested knowledge about palliative care was scant, though much valued when understood. Cultural and religious strictures on using palliative care services or a palliative care approach were not demonstrated, though others, including considerable concerns about food when an inpatient, were deemed of importance. The need to know what is locally available, and how to access those services, was uniformly agreed, and the information given warmly welcomed, even by those with reservations. http://www.ingentaconnect.com/content/rmp/dehc/2014/00000011/F0020003/art00008

Between worlds: The experiences and needs of former family carers

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 13 October 2014 – While the financial, physical and psycho-social burden for caregivers is recorded, less is known about the post-caring experience. For the participants in this study, post-caring was a transition that comprised three, interrelated, non-linear, iterative themes that were represented as "loss of the caring world," "living in loss" and "moving on" and symbolised as being "between worlds." Transition was a complex interplay of emotions overlaid with economic and social concerns that had implications for their sense of health and well-being. This exploratory study begins to address the dearth of data on post-caring/care experiences, but further research is needed to inform support interventions... http://onlinelibrary.wiley.com/doi/10.1111/hsc.12149/abstract

Experience with a hospital policy on not offering cardiopulmonary resuscitation when believed more harmful than beneficial

JOURNAL OF CRITICAL CARE | Online – 8 October 2014 – This study investigated the impact of age, race, and functional status on decisions not to offer cardiopulmonary resuscitation (CPR) despite patient or surrogate requests that CPR be performed. There were 134 cases of disagreement over whether to provide CPR. In 45 cases (33.6%), the patient or surrogate agreed to a do not resuscitate (DNR) order following initial ethics consultation. In 67 of the remaining 89 cases (75.3%), the ethics committee recommended not offering CPR. In the other 22 (24.7%) cases the ethics committee recommended offering CPR. There was no significant relationship between age, race, or functional status and the recommendation not to offer CPR. Patients who were not offered CPR were more likely to be critically ill... The 90-day mortality rate among patients who were not offered CPR was 90.2%. http://www.jccjournal.org/article/S0883-9441(14)00410-9/abstract

Noted in Media Watch, 13 October 2014, #379 (p.11):

- BRITISH MEDICAL ASSOCIATION, (U.K.) RESUSCITATION COUNCIL & THE ROYAL COLLEGE OF NURSING | Online – Accessed 8 October 2014 – **'Decisions relating to cardiopulmonary resuscitation.'** This new edition takes into account developments in clinical practice and developments in the law regarding anticipatory decisions about cardiopulmonary resuscitation. The guidance identifies key ethical and legal principles that should inform all CPR decisions. https://www.resus.org.uk/pages/DecisionsRelatingToCPR.pdf

Words matter: Distinguishing "personalized medicine" and "biologically personalized therapeutics"

JOURNAL OF THE NATIONAL CANCER INSTITUTE, 2014;106(12):dju321. "Personalized medicine" has become a generic term referring to techniques that evaluate either the host or the disease to enhance the likelihood of beneficial patient outcomes from treatment interventions. There is, however, much more to personalization of care than just identifying the bio-therapeutic strategy with the highest likelihood of benefit. In its new meaning, "personalized medicine" could overshadow the individually tailored, whole-person care that is at the bedrock of what people need and want when they are ill. http://jnci.oxfordjournals.org/content/106/12/dju321.short

Noted in Media Watch, 3 June 2013, #308 (p.9):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 27 May 2013 – **'Personalized medicine vs. guideline-based medicine.'** The conflict between guideline-based medicine and personalized medicine predominantly occurs when considering withholding a therapy that is recommended or supported by the guidelines but that may not be beneficial for an individual patient. http://jama.jamanetwork.com/article.aspx?articleid=1691756

A hospice-hospital partnership: Reducing hospitalization costs and 30-day readmissions among seriously ill adults

JOURNAL OF PALLIATIVE MEDICINE, 2014;17(9):1005-1010. Observational and randomized studies of cost savings associated with inpatient palliative care provide conflicting results, and the association with readmission is not well understood. On average, [in this study of 1,004 patients at two western New York hospitals] cost per admission was $1,401 (13%) lower among patients receiving palliative care than comparison patients... Cost reductions were evident within intensive care and laboratory services. Readmission rates were significantly lower among palliative care patients discharged with hospice care (1.1%) than comparison patients (6.6%), but significantly higher among palliative care patients discharged to other locations (12.1%). http://online.liebertpub.com/doi/full/10.1089/jpm.2013.0612?utm_campaign=&utm_medium=&utm_source=

Fears raised over staff shortage in palliative care

NURSING STANDARD, 2014;29(7):8. The quality of care for dying people could be put at risk because of a looming recruitment crisis in palliative care nursing, according to research. http://rcnpublishing.com/doi/abs/10.7748/ns.29.7.8.s4

Noted in Media Watch, 13 October 2014, #379 (p.7):

- U.K. (England) | National Council for Palliative Care – 9 October 2014 – **'The Specialist Palliative Care Workforce Survey.'** Key finding is the proportion of nurses working in palliative care aged over 50 continues to increase, potentially paving the way for a gap in palliative care nursing provision unless further work is undertaken to understand the reasons for the gaining workforce. http://www.ncpc.org.uk/sites/default/files/NCPC_SPC_Workforce_Survey_2013.pdf

Noted in Media Watch, 16 July 2012, #262 (p.10):

- *HEALTH LEADERS* | Online – 13 July 2012 – **'Palliative care challenged by physician shortage.'** While there is about one cardiologist for every 71 people experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative care physician for every 1,200 people living with a serious or life-threatening illness.[1] http://www.healthleadersmedia.com/content/MAG-282158/Palliative-Care-Challenged-by-Physician-Shortage

    1. 'Estimate of current hospice and palliative medicine physician workforce shortage,' *Journal of Pain & Symptom Management*, 2012;40(6):899-911 [Noted in Media Watch, 13 December 2010, #179 (p.9)] http://www.jpsmjournal.com/article/S0885-3924(10)00602-0/abstract

A call to action: An international work group charter for a public health approach to dying, death, and loss

OMEGA – JOURNAL OF DEATH & DYING, 2014;69(4):401-420. The current systems of care for dying persons, the people caring for them, and the bereaved operate in ways that frequently lack sufficient sensitivity to their needs. The authors describe a new model for dying, death, and loss that adopts a public health approach. Modeled after the World Health Organization's 1986 Ottawa Charter, their charter includes a call to action. It has the potential to bring about significant change on local, societal, and global levels as exemplified by four projects from three countries. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,4,6;journal,1,274;linkingpublicationresults,1:300329,1

Noted in Media Watch, 15 September 2014, #375 (p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 5 September 2014 – **'Using a public health approach to improve end-of-life care: Results and discussion of a health needs assessment undertaken in a large city in northern England.'** Patients and carers stressed the importance of communication, coordination and continuity of care; full involvement in care planning; honesty and support for the bereaved; an advocate for patients and families; accessible information; improved urgent care; integrated team working; pain relief, dignity and respect. http://spcare.bmj.com/content/early/2014/09/05/bmjspcare-2014-000662.abstract

Noted In Media Watch, 4 March 2013, #295 (p.11):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 22 February 2013 – **'Public health approaches to end-of-life care in the U.K.: An online survey of palliative care services.'** Of those providers [i.e., respondents] 60% indicated that public health approaches to death, dying and loss were a current priority for their organisation. The findings demonstrate the relevance of a public health approach for palliative care services and how they are currently engaging with the communities they serve. http://spcare.bmj.com/content/early/2013/02/22/bmjspcare-2012-000334.short

Pediatric bereavement services: A survey of practices at children's hospitals

OMEGA – JOURNAL OF DEATH & DYING, 2014;69(4):421-435. This study was designed to identify types of bereavement support offered to parents whose child died at a pediatric hospital, to ascertain who provides support and to see how those services are institutionally organized and funded. The investigation gathered data using an online, custom-designed survey completed by bereavement providers at 122 of the 188 pediatric hospitals invited to participate. This article summarizes the ways hospitals follow-up with families, from provision of educational materials to a menu of support services including memorial services, counseling, and community referrals. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,5,6;journal,1,274;linkingpublicationresults,1:300329,1

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Media Watch Online

International

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

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

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

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

Asia

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

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

Australia

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

Canada

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

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

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

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

Europe

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

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

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

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 16 October 2014 – **'Utilization of hospice bereavement support by at-risk family members.'** Hospices' bereavement services could potentially address needs of many at risk, but little is known about their service use. The authors analyzed data from 6,160 bereaved family members of hospice patients. Of those characterized as "at-risk," 52% used services compared to 18% of the "low risk." Factors associated with service use among at-risk were female gender and younger age of death. http://ajh.sagepub.com/content/early/2014/10/16/1049909114555155.abstract

Advance care planning and palliative medicine in advanced dementia: A literature review

THE PSYCHIATRIC BULLETIN | Online – 9 October 2014 – In total, 64 articles were found, including 12 reviews, and three key areas emerged: 1) barriers to advanced care planning; 2) raising awareness and fostering communication between professionals and patients; and, 3) disease-specific interventions. Most of the studies analysed were carried out in the U.S. or Europe. This narrative review aims to help guide future primary research, systematic reviews and, service development in the U.K. http://pb.rcpsych.org/content/early/2014/10/06/pb.bp.114.046896.abstract

Noted in Media Watch, 22 September 2014, #376 (p.9):

- *ALZHEIMER'S & DEMENTIA*, 2014;10(4):225. **'Dying well with dementia: Insights from qualitative studies of place of death and advance care planning.'** People with dementia often die badly, receiving end-of-life care of poorer quality than that given to the cognitively intact. Advanced care planning has the potential to improve end-of-life care in dementia. http://www.alzheimersanddementia.com/article/S1552-5260(14)00444-0/abstract

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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

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1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Noted in Media Watch, 8 September 2014, #374 (p.10):

- *DEMENTIA* | Online – 3 September 2014 – **'End-of-life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia: A qualitative study.'** Family caregivers need encouragement to ask the right questions during advance care planning to discuss the appropriateness of nursing and medical interventions at the end of life. http://dem.sagepub.com/content/early/2014/09/03/1471301214548521.abstract

Of related interest:

- *AIDS CARE PSYCHOLOGICAL & SOCIO-MEDICAL ASPECTS OF AIDS/HIV* | Online – 13 October 2014 – **'Advance directives among people living with HIV: Room for improvement.'** In this study, a small percentage of patients had documented advance directives, with only a small proportion completed in the HIV clinic ... an underutilized resource to... http://www.tandfonline.com/doi/abs/10.1080/09540121.2014.963019?queryID=%24%7BresultBean.queryID%7D

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