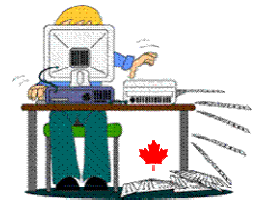


Media Watch...

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

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

Compiled & Annotated by Barry R. Ashpole

The "hands on" care at the end of life: Scroll down to [Specialist Publications](#) and 'Uncovering an invisible network of direct caregivers at the end of life: A population study' (p.12), in *Palliative Medicine*.

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ENVIRONICS RESEARCH GROUP | Online – 2 April 2013 – '**Canadians' attitudes towards end-of-life issues.**' Canadians are about twice as likely to support (63%) as to oppose (32%) a law allowing physician-assisted suicide in Canada, according to Environics Research. Support is slightly lower for legalizing euthanasia (55% vs. 40% who oppose it), which is likely due in part to providing respondents with information about the rate of euthanasia deaths occurring without patient consent in Belgium. In fact, relatively few Canadians are decisively in favour of legalizing these issues (29% in the case of assisted suicide and 18% in the case of euthanasia). Many of those expressing support do so with some hesitancy (i.e., say they "somewhat" support it), likely reflecting the concerns people have about such controversial topics. Support for assisted suicide is highest in B.C. (where the Supreme Court struck down the law against physician-assisted suicides), while support for euthanasia is highest in Quebec. Strong opposition to legalizing both issues is consistently higher among allophones and Canadians with lower socio-economic status (less education and lower incomes). Strong opposition to euthanasia is also higher among older Canadians and those with a physical or mental disability. <http://www.lifecanada.org/images/National%20Polls/Environics%20-%20LifeCanada%20Euthansia%20Report%202013%20-%20FINAL.pdf>

N.B. In a 2011 Environics poll, 95% of respondents wanted the government to make hospice and palliative care for the dying a high (66%) or medium (29%) priority. They wanted improved access to end of life care, but worry about the impact of legalized euthanasia on the elderly.

- LIBRARY OF PARLIAMENT | Background Paper (Publication No. 2010-68-E; Revised 13 February 2013) – 15 February 2013 – '**Euthanasia and Assisted Suicide in Canada.**' Background Papers provide in-depth studies of policy issues, featuring historical background, current information and references, and are prepared by the Parliamentary Information & Research Service, which carries out research for and provides information and analyses to parliamentarians and Senate and House of Commons committees and parliamentary associations. http://publications.gc.ca/collections/collection_2013/bdp-lop/bp/2010-68-1-eng.pdf

U.S.A.

Texas Senate approves end-of-life bill

TEXAS | *The Dallas Morning Star* – 19 April 2013 – The Senate has approved the first major revisions in the state's end-of-life law in more than a decade, giving patients and their families new safeguards and tripling the number of days for them to find a new facility when their current provider decides to end treatment. Patients and families will have the right to object to use of a 'Do Not Attempt Resuscitation' order and to ask an independent ethics committee to review the case. It also would ensure that pain management and comfort care may not be withheld from a patient at the end of life. <http://www.dallasnews.com/news/politics/state-politics/20130418-texas-senate-approves-end-of-life-bill.ece>

73% of people caring for an elderly family member admit lying to them

THE WALL STREET JOURNAL | Online – 19 April 2013 – Key findings of a survey of 700 people taking care of an elderly parent or family member: 73% admit to lying to the person they're caring for (43% on a regular, weekly basis); half who admit to lying believe it is justified because it either makes their own life easier or it's for the elderly family member's "own good"; only 28% of the people who lie believe it is wrong and feel guilty about it; family caregivers are most honest about their loved one's medical condition, and least honest about their own feelings; 65% lie about their own feelings; 39% lie about other family members; 20% lie about their loved one's health or well-being; 10% lie about their loved one's medical reports or test results. For those taking care of an elderly family member, striking a balance between honesty and keeping the peace often means bottling up unhealthy angst. http://online.wsj.com/article/PR-CO-20130419-911450.html?mod=googlenews_wsj

Quotable Quotes

*As individuals we go, at times, to extraordinary lengths in our day-to-day lives to avoid being the bearer of "bad news." We consciously work, it often seems, in overdrive – to "soften the blow," "sugar-coat the message," to be "politically correct" or "culturally sensitive." As a consequence, we risk living much of our lives evading truth. Are we losing the ability or capacity to communicate – or to hear what we need to hear – with empathy and without hurt or hurting? In our language usage, as an example, "openness" and "transparency" have replaced "honesty" and "truth," which are fundamental principles of end-of-life care ...but, is the "conspiracy of silence" that so often prevails as a death approaches – or when confronted with crises – nothing more than a manifestation of a life-long discomfort with acceptance of the inevitable or of the reality of a given situation – or with truth itself? **Barry R. Ashpole, extract from a lecture on 'Communications, Consent & Informed Decision Making,' 2007***

Hospice reimbursement cuts

Delaware Hospice lays off 52 more workers

DELAWARE | *The News Journal* (Wilmington) – 16 April 2013 – The layoffs impact all departments of the health care organization statewide, which employed roughly 400 people at the start of the year. A total of 104 people have been let go between January and now. Delaware Hospice, like other hospice and health care organizations throughout the country, is dealing with a 2% cut to Medicare reimbursement because of the federal sequester, which went into effect 1 April. http://www.delawareonline.com/article/20130416/BUSINESS13/304160057/Delaware-Hospice-lay-off-more-workers?nclick_check=1

Cont.

Noted in Media Watch, 15 April 2013:

- FLORIDA | *The Herald-Tribune* (Sarasota) – 11 April 2013 – **'Puzzling budget cuts for hospices.'** Despite evidence that hospice reduces Medicare spending hospices across the country are facing reimbursement cuts that could put some in jeopardy. These cuts will impact all hospices and could be particularly devastating for small hospices, which make up the majority of hospices in the U.S. <http://www.heraldtribune.com/article/20130412/COLUMNIST/304129996/-1/sports?Title=Gerry-Radford-Puzzling-budget-cuts-for-hospices>

Bill prohibiting end-of-life-care discrimination based on patient age, disability or terminal illness approved by Senate committee

OKLAHOMA | *Journal Record Legislative Report* (Oklahoma City) – Accessed 15 April 2013 – The Senate Committee on Health & Human Services approved a bill that would prohibit a health care provider from denying life-preserving treatment to a patient who has directed that he or she receive such care. House Bill 1403 – 'Non-discrimination in Treatment Act' – would ban denial of such care on the basis that extending the life of a patient who is elderly, disabled or terminally ill has less value than extending the life of someone who is younger, not disabled or not terminally ill. It also authorizes a legal action against a health care provider who violates the prohibition. <http://jrlr.net/>

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- VERMONT | VTDigger.org (The Vermont Journalism Trust) – 16 April 2013 – **'Vermont Alliance for Ethical Health Care says its poll shows Vermonters very much divided on physician assisted suicide bill.'** A poll commissioned by a non-profit organization opposed to Vermont enacting a law that would allow doctors to help terminally ill patients end their lives with prescription drugs found that more Vermonters support a doctor-assisted death bill based on an Oregon law than prefer the current legal situation. But after asking Vermonters a series of leading questions about concerns surrounding the bill, they shifted their responses to favor leaving the law as it is, without giving physicians immunity for following a highly regulated process for prescribing a lethal dose of medication. <http://vtdigger.org/2013/04/16/vermont-alliance-for-ethical-health-care-says-its-poll-shows-vermonters-very-much-divided-on-physician-assisted-suicide-bill/>
- MONTANA | *The New York Times* – 15 April 2013 – **'In Montana, new controversy over physician-assisted suicide.'** The Senate defeated House Bill 505, which would have mandated prison sentences and fines for physicians who provide aid in dying to terminally ill patients. The vote was 27 to 23 in opposition. <http://newoldage.blogs.nytimes.com/2013/04/15/a-montana-doctor-defends-physician-assisted-suicide/>

Noted in Media Watch, 15 April 2013:

- MONTANA | ABC News – 12 April 2013 – **'Montana doctors could face jail time for assisted suicide.'** The Senate gave a preliminary nod to a House-passed bill that would criminalize physician-assisted suicide. <http://abcnews.go.com/Health/montana-doctors-face-jail-time-assisted-suicide/story?id=18935792>

[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>

International

New end-of-life care delivery plan

Welsh government urges people to plan for end of life

U.K. (WALES) | BBC News – 18 April 2013 – Patients with incurable illnesses should have access to round the clock support and the best possible care leading up to their deaths. That is one of the commitments of a new plan by the Welsh government to offer better care to people at the end of their lives. The plan also says patients should be fully supported if they choose to die at home. <http://www.bbc.co.uk/news/uk-wales-22196744>

1. 'Together for Health – Delivering End of Life Care: A Delivery Plan up to 2016 for National Health Service Wales and its Partners. The highest standard of care for everyone at the end of life,' April 2013. <http://wales.gov.uk/docs/dhss/publications/130416careen.pdf>

N.B. The work of the Dying Matters Coalition is to be extended to Wales as part of the Welsh Government's new end of life care delivery plan. <http://www.dyingmatters.org/news/dying-matters-launch-wales>

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

A six-step guide to commissioning end of life care

U.K. | Royal College of General Practitioners – 16 April 2013 – 'Commissioning Guidance in End of Life Care' provides GPs and Clinical Commissioning Groups with a logical, six-step framework and overview to support their work in delivering practical improvements across the health, social care and voluntary and independent sectors. The guidance has been produced to ensure that the needs of dying patients and those closest to them are paramount whilst services are commissioned and developed around them. It advocates a broad approach that is locally tailored but based on national policy, guidance and current expert thinking. It cautions that improvements in treating long term conditions, dementia, frailty and reducing hospitalisation cannot be achieved unless end of life care is seriously considered and integrated. <http://www.rcgp.org.uk/news/a-six-step-guide-to-commissioning-end-of-life-care.aspx>

Of related interest:

- U.K. | General Medical Council – 25 March 2013 – **'Personal Beliefs and Medical Practice.'** The Council recognise that personal beliefs and cultural practices are central to the lives of doctors and patients, and that all doctors have personal values that affect their day-to-day practice. We don't wish to prevent doctors from practising in line with their beliefs and values, as long as they also follow the guidance in Good medical practice. Neither do we wish to prevent patients from receiving care that is consistent with, or meets the requirements of, their beliefs and values. http://www.gmc-uk.org/Personal_beliefs_and_medical_practice.pdf 514 62245.pdf

Extract from 'Personal Beliefs and Medical Practice'

If you have a conscientious objection – for example, to the withdrawal of life-prolonging treatment – you should follow the guidance in paragraphs 79-80 and 47-48 of our guidance 'Treatment and care towards the end of life: good practice in decision making' [at http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp]

Specialist Publications

'Palliative care program development: An international perspective' (p.9), in *Current Opinion in Supportive & Palliative Care*.

'Models of delivering palliative and end-of-life care in the U.K.' (p.9), in *Current Opinion in Supportive & Palliative Care*.

End-of-life care in Australia

Queensland goes its own way on 'advanced directives'

AUSTRALIAN (QUEENSLAND) | *The Brisbane Times* – 15 April 2013 – Before throat cancer and its treatment left Peter Browning "drug-addled and half-starved," the 53-year-old completed a long ... legal document known as an advance health directive. The directive recorded what medical care he would want to receive if he were unable to make decisions for himself. What Browning didn't know was that Queensland doctors can legally disregard a directive if they believe its instructions conflict with good medical practice. The Queensland Law Reform Commission wants the exemption removed. Taking the opposite stance, the Australian Medical Association has campaigned to have the exemption introduced nationally. In Australia, an adult patient has the legal right to refuse medical treatment. Queensland's Powers of Attorney Act states that a patient's refusal made in advance has the same status as regular refusals of medical intervention. But section 103 of the Act says doctors who reasonably believe instructions are "inconsistent with good medical practice" will not face "any liability" if they fail to follow a patient's directive. <http://www.brisbanetimes.com.au/queensland/queensland-goes-its-own-way-on-advanced-directives-20130415-2hvmz.html>

Media Watch Online

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

Canada

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

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

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

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

Europe

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

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

International

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)

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | BBC News – 18 April 2013 – **'Right to die debate.'** Paul Lamb is the latest person to seek a change in the law so that he can be allowed to die with the help of a doctor.¹ His case continues the same legal challenge mounted by the late Tony Nicklinson, who also wanted the right to seek medical assistance to end his life. These cases go beyond those of Diane Pretty and Debbie Purdy, who wanted to challenge laws on "assisted suicide" – to protect their husbands if they helped them to die. Despite all legal challenges, there has been no change in U.K. law on either point. <http://www.bbc.co.uk/news/health-22198464>

1. 'Right to die: Paul Lamb takes up Tony Nicklinson fight,' BBC News, 18 April 2013. <http://www.bbc.co.uk/news/uk-22191059>

N.B. Links to reports pertaining to Nicklinson, Pretty and Purdy are embedded in the BBC report.

[Specialist Publications](#)

'Escaping the shackles of law at the end of life: R (Nicklinson) v Ministry of Justice...' (p.14), in *Medical Law Review*.

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

Hospitals teach being "conversation-ready" for end-of-life care

AMERICAN MEDICAL NEWS | Online – 15 April 2013 – Physicians and hospitals are broadening their efforts to help patients and families talk earlier about their preferences for end-of-life care. One of the newer initiatives is the Conversation Project, launched by a coalition of doctors, health care executives and others.¹ Earlier efforts such as Aging With Dignity's Five Wishes program have as their goal the creation of legally enforceable advance directives and designation of health care proxies.² The Conversation Project focuses on providing patient- and family-focused educational materials to help in broaching these difficult discussions. The need for action is great. Less than half of severely or terminally ill patients have an advance directive, according to the Agency for Healthcare Research & Quality. Twelve percent of patients who have such a document got input from a physician in creating it. About 30% of patients told the Pew Research Center in 2006 that they had a living will. But a February 2012 California Health-Care Foundation poll of nearly 1,700 adults found that only 8% had ever been asked by a doctor about end-of-life treatment wishes. <http://www.amednews.com/article/20130415/profession/130419978/6/>

Questions to start end-of-life care conversations

An initiative co-sponsored by the Institute for Healthcare Improvement provides questions that can get the discussion going.³

When you think about the last phase of your life, what's most important to you? How would you like this last phase to be?

Do you have any particular concerns about your health? About the last phase of your life?

Who do you want — or not want — to be involved in your care? Who would you like to make decisions on your behalf if you're not able to?

Would you prefer to be actively involved in decisions about your care? Or would you rather have your doctors do what they think is best?

Are there any disagreements or family tensions that you're concerned about?

Are there circumstances that you would consider worse than death? (For example: long-term need of a breathing machine or feeding tube, or not being able to recognize your loved ones.)

Are there important milestones you'd like to meet if possible?

Cont.

1. The Conversation Project: <http://theconversationproject.org/>
2. Five Wishes, Aging with Dignity: <http://www.agingwithdignity.org/five-wishes.php>
3. Institute for Healthcare Improvement's "conversation ready" initiative: <http://www.ihl.org/offerings/Initiatives/ConversationProject/Pages/ConversationReady.aspx>

Psychological issues in voluntary hospice care

BRITISH JOURNAL OF NURSING, 2013;22(7):377-383. Hospices require a multidisciplinary team of health workers to ensure that patients receive appropriate palliative care. One way to tackle this challenge has been to rely increasingly on volunteer carers. Recruiting and retaining volunteers requires some understanding of the psychological challenges (thoughts, emotions and actions) associated with voluntary care. Nine voluntary carers in one U.K. hospice were interviewed about their experiences. Five major themes emerged: motivation to volunteer, volunteering skills, psychological support and holistic care, positive perceptions of the hospice, and performance hindrances. The skills theme (reflecting abilities acquired from previous experience) was especially prominent. Overall, a model emerged suggesting that volunteers experience cognitive-affective-behavioural challenges involving themselves, patients and the work environment. Self-related challenges seem especially prominent. http://www.britishjournalofnursing.com/cgi-bin/go.pl/library/article.html?uid=97989;article=BJN_22_7_377_383

Of related interest:

- *OMEGA – JOURNAL OF DEATH & DYING*, 2013;66(4):281-299. **'The psychological experience of hospice workers during encounters with death.'** While the nature of their experience is unknown, hospice workers may unconsciously strive for encounters with death as a way of healing themselves and preparing for death. This study explores the psychological experience of hospice workers, whose repeated encounters with death may affect their own psyche. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue_1_8;journal_1_263;linkingpublicationresults_1:300329_1

Noted in Media Watch, 7 January 2013:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 31 December 2012 – **'Promoting volunteer capacity in hospice palliative care: A narrative review.'** A substantial body of evidence exists describing the roles, stresses and rewards of hospice volunteering. Less is known about how to adequately recruit, prepare and retain volunteers. <http://ajh.sagepub.com/content/early/2012/12/28/1049909112470485.abstract>

Noted in Media Watch, 23 July 2012:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 July 2012 – **'Holding on to what you have got: Keeping hospice palliative care volunteers volunteering.'** The items that received the highest mean importance ratings [in this study] included enjoying the work they do, feeling adequately prepared/trained to perform their role, and learning from their patients' experiences/listening to their patients' life stories. Being recognized, receiving phone calls/cards from their volunteer coordinator on special occasions, and being reimbursed for out-of-pocket expenses were among the items that received the lowest mean importance ratings. <http://ajh.sagepub.com/content/early/2012/07/16/1049909112453643.abstract>

Noted in Media Watch, 16 January 2012:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 January 2012 – **'Should I stay or should I go: A study of hospice palliative care volunteer satisfaction and retention.'** In 5 of the 9 programs [studied], volunteers said that feeling appreciated by the patients/families they support gave them great satisfaction. Boundary issues and/or role ambiguities were among the least satisfying aspects of their work, mentioned by volunteers in 4 programs. <http://ajh.sagepub.com/content/early/2012/01/04/1049909111432622.abstract>

Cont.

Noted in Media Watch, 14 February 2011:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 10 February 2011 – **'Boundary issues for hospice palliative care volunteers: When to say "yes" and when to say "no."**' The authors distinguished between "definite boundary issues" (things volunteers should never do, for example, "accept money from a patient or family"), "potential boundary issues" (things volunteers should stop and think twice about doing, for example, "accept a gift from a patient or family"), and "questionable boundary issues" (things volunteers should be aware of doing, for example, "give your home phone number to a patient or family"). The implications for training volunteers are discussed and the need for clear and unambiguous organizational policies and procedures to preserve boundaries is stressed. Without clear policies, etc., community-based hospice programs may be putting themselves at legal risk. <http://ajh.sagepub.com/content/early/2011/02/08/1049909110397926.abstract>

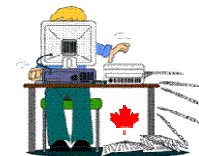
When a patient dies

Compassion fatigue

CANADIAN FAMILY PHYSICIAN, 2013;59(3):265-268. Physicians do experience reactions to the deaths of their patients, although it is not a topic often talked about or researched. A quantitative and qualitative study identified that physicians early in their training and career found deaths more shocking and disturbing than more experienced physicians did.¹ The same article noted that physicians' emotional responses were influenced by their own personal experiences with losses, the degree to which they identified or felt close to the patients, and the degree to which they felt responsible for the patients' deaths. Another study done in the U.S. found that the longer a physician had been caring for a patient, the more satisfying but also the more emotionally distressing the patient's death could be.² This is certainly the case for family physicians who might have known their patients for many years before their deaths. What both articles noted was the lack of discussion of these emotional responses among physicians, particularly between trainees and their teachers. <http://171.66.125.180/content/59/3/265.short>

1. "'It was haunting [horizontal ellipsis]': Physicians' descriptions of emotionally powerful patient deaths,' *Academic Medicine*, 2005;80(7):648-656. Physicians' emotional reactions to patient death can affect patient care and the personal lives of physicians. Supervising physicians have an opportunity to improve both the care of dying patients and house-staff coping with these deaths by using the teachable moments that are present for trainees as they care for the dying. http://journals.lww.com/academicmedicine/Fulltext/2005/07000/It_was_haunting_horizontal_ellipsis_.7.aspx
2. 'Doctors' emotional reactions to recent death of a patient: Cross sectional study of hospital doctors,' *British Medical Journal*, 2003;327(7408):185. Doctors who spend a longer time caring for their patients get to know them better but this also makes them more vulnerable to feelings of loss when these patients die. Medical teams may benefit from debriefing within the department to give junior doctors an opportunity to share emotional responses and reflect on the patient's death. <http://www.bmj.com/content/327/7408/185.pdf%2Bhtml>

Barry R. Ashpole



My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or 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 courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

Palliative care program development: An international perspective

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 6 April 2013 – When Dame Cicely Saunders founded St. Christopher's Hospice in 1967, linking for the first time the triad of clinical care, education, and research in what would become the field of palliative care, it is unlikely that she imagined how far her vision would ultimately spread. In this edition of *Current Opinion in Supportive & Palliative Care*,¹ we review the different models of palliative care delivery, with perspectives from the U.K., the U.S., Japan, India, and sub-Saharan Africa. The five models of palliative care across all care settings remains a priority and also show that we can learn as much from the developing models in resource-poor nations as we can from more well established programs. <http://www.ncbi.nlm.nih.gov/pubmed/23572160>

1. Contents page: <http://journals.lww.com/co-supportiveandpalliativecare/toc/publishahead>

Of related interest:

- *CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 15 April 2013 – **'Models of delivering palliative and end-of-life care in the U.K.'** The main focus of this review is to describe adult palliative care services in England, although much of the historical developments apply across the whole of the U.K., and some of the later developments affect children's services as well. Although there is comprehensive coverage of palliative care obtainable across the U.K. and good access to medication and equipment, there remains a lot of inequity to challenge and address, including those relating to geography, diagnosis, age and ethnicity. http://journals.lww.com/co-supportiveandpalliative-care/Abstract/publishahead/Models_of_delivering_palliative_and_end_of_life.99763.aspx

"Being there"

The experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES, 2013;26(3):215-230. Research on staffed housing for people with intellectual disability has identified the challenges in achieving positive quality of life outcomes. However, a less well considered dimension of such services is that they are places of living and dying. This paper looks at the experiences of staff in dealing with issues of death and dying. Staff [i.e., study participants] felt providing a good quality of care at the end of life was an important but unrecognised dimension of their work. This work could be broken down into several different phases, dying, death and beyond death. Bad deaths were felt to be those deaths which prevented staff from "being there" with individuals over those phases. <http://onlinelibrary.wiley.com/doi/10.1111/jar.12024/abstract>

N.B. This issue of the journal focuses on several aspects of dying and death and people living with intellectual disabilities. Contents page: <http://onlinelibrary.wiley.com/doi/10.1111/jar.2013.26.issue-3/issuetoc>

Noted in Media Watch, 4 February 2013:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(1):48-50. **'Palliative Care for People with Learning Disabilities Network.'** How people with intellectual disabilities are supported at the end of life is dependent on the place they have in society and their level of integration; on the training and attitudes of those who provide care for people with intellectual disabilities; and, on the availability of palliative care services for the general population. <http://www.eapcnet.eu/LinkClick.aspx?fileticket=8Plz1FAom1k%3d&tabid=1622>

Cont.

Noted in Media Watch, 26 November 2012:

- *AMERICAN JOURNAL ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES*, 2012; 117(6):509-532. **'Unique and universal barriers: Hospice care for aging adults with intellectual disability.'** This article presents a review of the literature ... underscoring the multiple challenges and the importance of a more collaborative approach between hospice and palliative care workers with people with intellectual disabilities, their families, and other important stakeholders. <http://www.aaidjournals.org/doi/abs/10.1352/1944-7558-117.6.509>

Appropriate, timely referral to palliative care services: A name change will not help

JOURNAL OF CLINICAL ONCOLOGY | Online – 8 April 2013 – Given the negative views and misperceptions about palliative care held by patients, family members and health professionals, the authors developed the Perceptions of Palliative Care Instrument [see sidebar, right]. To date, this instrument has only been used in a research setting. It was designed to be completed by patients thought likely to benefit from community-based specialized palliative care services so that responses can be used by health professionals to guide the introductory discussion and address misconceptions. The authors hope this will facilitate appropriate and timely discussions about palliative care and overcome patient barriers to referral. Rather than changing the name from "palliative care," risking ambiguity and confusion, they believe that improved communication is key to appropriate engagement with palliative care services. Understanding what patients

and caregivers interpret palliative care to mean, correcting misconceptions, and educating people about the value that palliative care services can provide are essential. <http://jco.ascopubs.org/content/early/2013/04/08/JCO.2012.48.4493.full.pdf+html?sid=403ed8f5-8adb-4d61-ac1a-9eda415b7853>

Development and validation of a measurement tool to assess perceptions of palliative care

PSYCHO-ONCOLOGY, 2013;22(4):940-946. The Perceptions of Palliative Care Instrument ... a four-factor, 37-item measure that assesses perceptions of palliative care held by patients with advanced cancer ... has good internal consistency, test-retest reliability and convergent validity. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3071/abstract>

Noted in Media Watch, 15 April 2013:

- *THE ONCOLOGY REPORT* | Online – 10 April 2013 – **'What's in a name: Is the moniker "palliative care" too loaded?'** A survey of 169 patients with advanced cancer found those randomized to hear the term "supportive care" instead of "palliative care" rated their understanding, overall impressions and future perceived need for those services significantly higher. <http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/what-s-in-a-name-is-the-moniker-palliative-care-too-loaded/15b05715fc83fdc88503a88bc9cbfc0e.html>

Settings of care within hospice: New options and questions about dying "at home"

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2013;15(3):171-176. Although place of death has been routinely studied in end-of-life care, more analysis on place of death within hospice is needed because of the recent, dramatic rise in the number of hospice patients dying in inpatient settings. This article highlights ... factors and elucidates gaps for further research. Individual- and system-level factors, socio-cultural meanings, caregiving, and preferences are shown to have important implications. The unique components of home hospice, inpatient hospice, and transitions between these settings may have a fundamental role in the future of quality end-of-life care. http://journals.lww.com/jhpn/Abstract/2013/05000/Settings_of_Care_Within_Hospice_New_Options_and.9.aspx

Pediatric palliative care research comes of age: What we stand to learn from children with life-threatening illness

JOURNAL OF PALLIATIVE MEDICINE, 2013;16(4):334-336. This issue of the journal includes three articles ... to inform the provision of palliative care for children with life-threatening illness and their families.^{1,2,3} They highlight innovative strategies to reduce suffering and improve the well-being of seriously ill children and families. Nevertheless, it is worthwhile noting the nature of these studies, based on a limited sample, are emblematic of the current state of the science in pediatric palliative care research. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.9518>

1. 'Developing a pediatric palliative care service in a large urban hospital: challenges, lessons, and successes.' <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0187>
2. 'Journey from pediatric intensive care to palliative care.' <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0448>
3. 'Treatment with gabapentin associated with resolution of apnea in two infants with neurologic impairment.' <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0103>

Noted in Media Watch, 8 April 2013:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 April 2012 – '**Pediatric palliative care in Canada and the U.S.: A qualitative Meta-summary of the needs of patients and families.**' Findings were grouped into domains pertaining to patient and family needs: interactions with staff, health care delivery and accessibility, information needs, bereavement needs, psychosocial needs, spiritual needs, pain and symptom management, cultural needs, sibling's needs, and decision making. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0076>

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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.

Uncovering an invisible network of direct caregivers at the end of life: A population study

PALLIATIVE MEDICINE | Online – 15 April 2013 – Most palliative care research about caregivers relies on reports from spouses or adult children. Some recent clinical reports have noted the assistance provided by other family members and friends. This population study aims to define the people who actually provide care at the end of life. People of all ages indicated they provided "hands on" care at the end of life. Extended family members (not first degree relatives) and friends accounted for more than half of identified hands-on caregivers. These people came from the entire age range of the adult community. The period of time for which care was provided was shorter for this group of caregivers. People with extended family or friends providing care, were much more likely to be supported to die at home compared to having a spousal carer. This substantial network of caregivers who are mainly invisible to the health team provide the majority of care. Hospice and palliative care services need to create specific ways of identifying and engaging this cohort in order to ensure they are receiving adequate support in the role. Relying on "next-of-kin" status in research will not identify them. <http://pmj.sagepub.com/content/early/2013/04/11/0269216313483664.abstract>

Should palliative care patients' hope be truthful, helpful or valuable? An interpretative synthesis of literature describing healthcare professionals' perspectives on hope of palliative care patients

PALLIATIVE MEDICINE | Online – 15 April 2013 – Three perspectives on hope ... were found: 1) realistic perspective – hope as an expectation should be truthful, and healthcare professionals focused on adjusting hope to truth; 2) functional perspective – hope as coping mechanism should help patients, and professionals focused on fostering hope; and, 3) narrative perspective – hope as meaning should be valuable for patients, and healthcare professionals focused on interpreting it. Healthcare professionals who are able to work with three perspectives on hope may improve their communication with their palliative care patients, which leads to a better quality of care. <http://pmj.sagepub.com/content/early/2013/04/11/0269216313482172.abstract>

Death with dignity from the perspective of the surviving family: A survey study among family caregivers of deceased older adults

PALLIATIVE MEDICINE | Online – 11 April 2013 – While research results have been published on what patients themselves believe may affect the dignity of their deaths, little is known about what family caregivers consider to be a dignified death. 69% [of study participants] reported their relative had died with dignity. Factors associated with a dignified death ... were patients feeling peaceful and ready to die, absence of anxiety and depressive mood, presence of fatigue, and a clear explanation by the physician of treatment options during the final months of life. <http://pmj.sagepub.com/content/early/2013/04/09/0269216313483185.abstract>

Understanding the concept of a "good death" among bereaved family caregivers of cancer patients in Singapore.'

PALLIATIVE & SUPPORTIVE CARE, 2013;11(1): 37-46. Whereas there are global attributes of a good death, findings suggest patients and family caregivers may define a good death differently. Therefore, there is a need to respect, address, and reconcile the differences, so all parties may have a good experience at the end of a person's life. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8826303>

Cont.

Noted in Media Watch, 12 November 2012:

- *PHILOSOPHY, PSYCHIATRY & PSYCHOLOGY*, 2012;19(3):187-189. **'Hope as virtue: Opens up a new space for exploring hopefulness at the end of life and raises some interesting questions.'** Considering hope as a virtue involves taking a fresh perspective where the grounds for possessing and expressing hope can be examined. As with the other virtues, presumably for hope there exists a "golden mean." The golden mean of courage lies between timidity and reckless abandonment to danger; "virtuous" hope lies between despair, where there is no hope at all, and extreme optimism, where hope does not have any grounding in reality. Realistic hope can exist without any great chance of the hoped-for event materializing. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/philosophy_psychiatry_and_psychology/v019/19.3.munday.html
- *PHILOSOPHY, PSYCHIATRY & PSYCHOLOGY*, 2012;19(3):165-181. **'From hope in palliative care to hope as a virtue and a life skill.'** This paper aims at explicating a theory of hope that is suitable for gravely ill people based on virtue ethics, research in the psychology of "well-being," and the philosophy of palliative care. Hope is the valuation of and personal identification with "promotion-focus" goals with an attitude of non-attachment to any one goal. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/philosophy_psychiatry_and_psychology/v019/19.3.barilan.html

Noted in Media Watch, 20 April 2009:

- *JOURNAL OF CLINICAL ONCOLOGY*, 2009;27(10):1722-1723. **'Another infusion of hope.'** Some oncologists support explicit communication that makes patients aware of their destinies, so they can attend to all practical, personal, and family issues in due time. Others emphasize the desire to maintain hope is strongly linked to human nature and patients really do not want or need to know accurate prognostic information; therefore, communication should be tempered, even if the patient asks for prognostic information. This approach, known as necessary collusion, purposely leaves a certain degree of uncertainty in prognostic estimation to keep hope alive. <http://jco.ascopubs.org/cgi/content/full/27/10/172>

Noted in Media Watch, 13 April 2009:

- *CLINICAL ETHICS*, 2009;4(1):38-43 **'Hope and terminal illness: false hope versus absolute hope.'** Sustaining hope in patients is an important element of health care, allowing improvement in patient welfare and quality of life. However in the palliative care context ... it might seem that in order to maintain hope the palliative care practitioner would sometimes have to deceive the patient about the full nature or prospects of their condition by providing a "false hope." <http://ce.rsmjournals.com/cgi/content/abstract/4/1/38>

The role of palliative care in the current HIV treatment era in developed countries

TOPICS IN ANTIVIRAL MEDICINE, 2013;21(1):20-26. In the early years of the AIDS epidemic in developed countries, prognosis was poor and palliative care was often inseparable from HIV care. Despite the advent of effective antiretroviral therapy and its availability in developed countries, patients with HIV disease still present many palliative care challenges and opportunities. The cases of 3 HIV-infected patients who embody these challenges will be presented in this article: an older patient with numerous medical co-morbidities, chronic pain, and severely impaired physical function; a patient with psychiatric illness and substance abuse, difficulties with adherence to antiretroviral therapy and retention in HIV primary care, and cryptococcal meningitis; and a patient with stable HIV disease and hepatitis C virus-related liver failure. These cases are being presented to stimulate a discussion between HIV and palliative care practitioners about potential areas of clinical and research collaboration. <https://www.iasusa.org/sites/default/files/tam/21-1-20.pdf>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *MEDICAL LAW REVIEW* | Online – 18 April 2013 – '**Escaping the shackles of law at the end of life...**' This commentary on *R (Nicklinson) v Ministry of Justice* argues that the court should have allowed the use of the defence of necessity. The official response of the law should be to outlaw euthanasia or assisted suicide, but also to recognise that in exceptional circumstances these should be permitted. The author argues the treatment of suicidal and elderly people is a far more important issue than creating the correct legal response to assisted dying. <http://medlaw.oxfordjournals.org/content/early/2013/04/18/medlaw.fwt004.abstract>
- *MEDICINE, HEALTH CARE & PHILOSOPHY*, 2013;16(2):225-230. '**Autonomy-based arguments against physician-assisted suicide and euthanasia: A critique.**' Respect for autonomy is typically considered a key reason for allowing physician assisted suicide and euthanasia. However, several recent papers have claimed this to be grounded in a misconception of the normative relevance of autonomy. It has been argued that autonomy is properly conceived of as a value, and that this makes assisted suicide as well as euthanasia wrong, since they destroy the autonomy of the patient. This paper evaluates this line of reasoning by investigating the conception of valuable autonomy. Starting off from the current debate in end-of-life care, two different interpretations of how autonomy is valuable is discussed. According to one interpretation, autonomy is a personal prudential value, which may provide a reason why euthanasia and assisted suicide might be against a patient's best interests. According to a second interpretation, inspired by Kantian ethics, being autonomous is unconditionally valuable, which may imply a duty to preserve autonomy. The authors argue that both lines of reasoning have limitations when it comes to situations relevant for end-of life care. It is concluded that neither way of reasoning can be used to show that assisted suicide or euthanasia always is impermissible. <http://link.springer.com/article/10.1007/s11019-011-9365-5>
- *NEW ENGLAND JOURNAL OF MEDICINE*, 2013;368(15):1450-1452. '**Physician-assisted suicide.**' [In this case study] do you believe that Mr. Wallace should be able to receive life-terminating drugs from his physician? Which one of the following approaches to the broader issue do you find appropriate? Base your choice on the published literature, your own experience, and other sources of information. To aid in your decision making, each of these approaches is defended in the following short essays by experts in the field. Given your knowledge of the patient and the points made by the experts, which option would you choose? <http://www.nejm.org/doi/full/10.1056/NEJMcide1302615>

Worth Repeating

A good death: Exit strategies

HARPERS MAGAZINE, 2010;November:36-52. If we could only "understand" death (which is to say, if a virgin could only comprehend sexual experience), then death's tyranny upon our thoughts might weaken. And so we formulate from our experience, as did my grandfather, who was once burglarized by a black man and therefore had the black race all figured out. Two elderly women have passed away in my neighbor's arms, and she, because both died in terror, conceptualizes death as a process that necessarily involves fear. Thanks to these cautionary examples, I will not presume to tell you what death is. Let me content myself with this: There must be better or worse ways to die. It seems both rational and possible to minimize the likelihood of an unpleasant end. <http://www.harpers.org/archive/2010/11/0083180>

Barry R. Ashpole
Beamsville, Ontario CANADA

'phone: 905.563.0044
e-mail: barryashpole@bellnet.ca