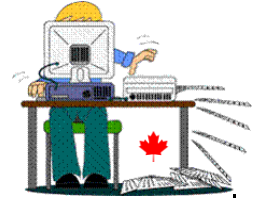


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Provision and delivery of end-of-life care in rural areas and small communities: Scroll down to [Specialist Publications](#) and 'Understanding the distinct experience of rural inter-professional collaboration in developing palliative care programs' (p.10), in *Rural & Remote Health*.

Canada

Matthews House Hospice caught in endless funding battle

ONTARIO | *The Alliston Herald* – 16 May 2014 – Three years ago, Matthews House Hospice put plans into motion to give South Simcoe residents a better option for end-of-life care. After conducting a needs assessment that showed four to five palliative care beds were needed for the community, the hospice, without a funding commitment from the province, opened its temporary residential hospice this past summer in Alliston. "We felt that we could demonstrate how successful and efficient we could operate our hospice," said board president Marv Chantler. "As well, we would prove that we could save our health system money by moving clients from the hospital to the hospice so they could die with dignity in a home-like setting." It costs about \$400,000 to run the four-bed facility. Including the \$300,000 needed to run the visiting hospice, the total annual operating cost works out to about \$700,000. The organization receives \$38,000 in operation funding for the visiting hospice through a transfer payment from Stevenson Memorial Hospital. After Mat-

thews House separated from Hospice Simcoe in 2008, the province gave it an annual operating budget of \$36,000 based on the forty clients it had at the time. Today, Matthews House has about 370 clients relying on the array of counselling and caregiver support services. While there is no funding in place for the residential hospice, it does receive about \$200,000 worth of care services through the Community Care Access Centre for personal support workers. <http://www.simcoe.com/news-story/4520774-matthews-house-hospice-caught-in-endless-funding-battle/>

Extract from *The Alliston Herald* article

In conservative numbers, hospital beds are valued at two levels – \$500 per day for Alternative Level of Care and \$700 per day for Acute Care. Based on the \$90,000 per bed funding model, the average daily cost to care for someone at the residential hospice is about \$250.

Population trends

Life expectancy in Canada hits 80 for men, 84 for women

CBC NEWS | Online – 15 May 2014 – Life expectancy in Canada and other countries around the world is growing, according to a new report from the World Health Organization, with most of the progress apparent in low-income countries.¹ In Canada, average life expectancy for males born in 2012 is 80 and for females 84, the agency said. In comparison, males born in Canada in 1990 could expect to live to 74 and females to 81 on average. For both sexes in Canada, life expectancy increased on average from 77 in 1990 to 82 in 2012. Low-income countries have made the most progress, with an average increase in life expectancy by nine years from 1990 to 2012. <http://www.cbc.ca/news/health/life-expectancy-in-canada-hits-80-for-men-84-for-women-1.2644355>

1. 'World Health Statistics 2014: A wealth of information on global health.' (Summary) http://apps.who.int/iris/bitstream/10665/112739/1/WHO_HIS_HSI_14.1_eng.pdf?ua=1

U.S.A.

It's better to die at home, but many people are scared to talk about it

THE NEW YORK MAGAZINE | Online – 16 May 2014 – We know it's hard to talk about death. New research highlights why we should get better at it.¹ For the study, researchers asked caregivers of 402 people who died of cancer between 2005 and 2010 in Toronto to fill out the Quality of Dying & Death (QODD) questionnaire, a clinically respected measure for gauging what researchers call "quality of death" – that is, to what extent the person who died was comfortable, free of painful symptoms, and so on. Overall, the caregivers rated the quality of these deaths pretty highly – 39% were in the "good" to "almost perfect" range of the QODD scale, while 61% were in the "neither good nor bad" range. That doesn't tell us a

huge amount, though, because as the researchers point out, this is an affluent patient sample that comes from a city (and country) with a very good health-care system. What is telling is the percentage of patients who didn't die at home. <http://nymag.com/scienceofus/2014/05/how-to-die-better.html>

Specialist Publications

'Staying at home: Risk, accommodation, and ethics in hospice care' (p.7), in *Journal of Hospice & Palliative Nursing*.

1. 'The quality of dying and death in cancer and its relationship to palliative care and place of death,' *Journal of Pain & Symptom Management*, 4 April 2014. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00149-3/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00149-3/abstract)

Lifting from others the burden of your own death

THE NEW YORK TIMES | Online – 14 May 2014 – As you journey toward your end, "dreading and hoping all," to quote Yeats, there is a lot to ponder. Assuming that you have fully documented your intentions for your estate and charitable giving, there is the looming and difficult subject of death planning. For most, it's akin to doing taxes and having a root canal in the same day. Although death planning can be emotionally vexing, it is essential for families and survivors. They may not know your true intentions without written directives. By the time the will is read or estate plan executed, it will be too late. Yet death planning will not only allow you to plan a dignified, meaningful and even splashy exit, but will provide guidance for those attending to your last moments and beyond. http://www.nytimes.com/2014/05/15/business/retirementspecial/proper-death-planning-is-a-final-gift-to-loved-ones.html?_r=0

Under new Medicare model, members may not have to choose between treatment and hospice

REUTERS | Online – 14 May 2014 – A new program from the Centers for Medicare & Medicaid Services may remove a barrier that makes patients hesitate to opt for hospice care near the end of life. Until now, to receive hospice care, patients had to agree to forego any further attempts at curative treatments. The new Medicare Care Choices Model will soon offer an option for Medicare beneficiaries to receive palliative care services from certain hospices while still receiving treatment from curative care providers. <http://www.reuters.com/article/2014/05/14/us-curative-hospice-medicare-idUSKBN0DU1P220140514>

Of related interest:

- RHODE ISLAND | WPRI Eyewitness News (Providence) – 14 May 2014 – **'Governor signs bill expanding care for seriously ill.'** Governor Lincoln Chafee signed a bill that expands care options for seriously ill patients in Rhode Island. The new law establishes a state advisory council on palliative care and quality of life, as well as palliative care consumer and professional information and education program and access initiative. <http://wpri.com/2014/05/14/ri-gov-signs-bill-expanding-care-for-seriously-ill/>

International

Call for a new Scottish Government strategy to improve end-of-life care in Scotland

U.K. (Scotland) | Scottish Partnership for Palliative Care – 16 May 2014 – Marie Curie Cancer Care and the Scottish Partnership for Palliative Care have published a report which calls on the Scottish Government to act on recent promises to replace *Living & Dying Well: A national action plan for palliative and end-of-life care in Scotland*.¹ It's now been six years since the publication of *Living and Dying Well* in September 2008 and although progress has been made, challenges remain. Earlier this year over 80 people with an interest in palliative care including MSPs gathered in Edinburgh to discuss its successes. The report of that gathering confirms the urgent need for a broad reaching new framework for action. In *Are We Living & Dying Well Yet* the authors have set out steps to meet the challenge of improving experiences of death, dying and bereavement for the people of Scotland. <http://www.palliativecarescotland.org.uk/content/publications/Are-We-Living-and-Dying-Well-Yet-FINAL-REPORT.pdf>

1. *Living & Dying Well: A national action plan for palliative and end-of-life care in Scotland*, The Scottish Government, 2008. <http://www.scotland.gov.uk/Resource/Doc/239823/0066155.pdf>

End-of-life in the U.K.

End of life care requires "wide scale improvements," report says

U.K. (England) | *The Guardian* – 15 May 2014 – Fewer than half of National Health Service patients who were in their last hours or days were told that they were dying by hospital staff, according to a critical report from the Royal College of Physicians, while a significant number of families and relatives are left feeling they have no emotional support.¹ The report also highlights the continued lack of specialist palliative care at weekends, 10 years on from National for Health & Care Excellence recommendations that it should be offered seven days a week. Complaints by families that dying relatives were not given fluids were one of the chief spurs to an investigation and later withdrawal of The Liverpool Care Pathway, a protocol intended to help people to die well. <http://www.theguardian.com/society/2014/may/15/end-of-life-care-uk-improvements-nhs-patients>

1. 'National Care of the Dying Audit of Hospitals,' Royal College of Physicians, 14 May 2014. <http://www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW ZEALAND | TV NZ News – 12 May 2014 – **'Euthanasia report warns of elder abuse.'**
A report into euthanasia warns that the potential for abuse and flouting of safeguards is a strong argument against legalisation.¹ Safeguards can only go so far and coercion is subtle, the report by Rex Ahdar of Otago University says. The report notes that most of the medical profession and national medical associations around the world have been resolutely against the introduction of voluntary euthanasia or physician-assisted suicide, amidst real concerns that the role of the doctor would be irrevocably changed from healer to, at times, killer. The report concludes that any decriminalisation of euthanasia will introduce the era of "therapeutic killing." <http://tvnz.co.nz/national-news/euthanasia-report-warns-elder-abuse-5969035>
- 1. 'Killing me softly: Should euthanasia be legalised?' Report to Family First New Zealand 2014. <http://www.familyfirst.org.nz/wp-content/uploads/2014/05/Killing-Me-Softly-Report.pdf>

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

Opportunities for psychologists in palliative care: Working with patients and families across the disease continuum

AMERICAN PSYCHOLOGIST, 2014;69(4):364-376. Interdisciplinary palliative care services have been rapidly expanding in health care settings over the past 10 years, particularly through the establishment of interdisciplinary palliative care teams. Relatively few of these teams formally include psychologists, although their skills of enhancing patients' and families' well-being and lessening suffering make an enormous contribution to the care provided. The authors define palliative care in broad terms, distinguishing it from hospice and end-of-life care. Using a case-based approach, they then explore the contribution of psychologists to the patient- and family-centered approach espoused by palliative care, including the knowledge, skills, and self-awareness needed to work effectively with these very ill patients and their families. The authors close with a call to action to better train and integrate psychologists into the rapidly growing field of palliative care. <http://www.apa.org/pubs/journals/releases/amp-a0036735.pdf>

New bereavement care service standards [in the U.K.]

BEREAVEMENT CARE | Online – 9 May 2014 – The new Bereavement Care Service Standards set out what needs to be addressed in order for services to be both safe and effective in meeting the needs of bereaved people.¹ Launched in January 2014, they have been developed to apply to all services providing bereavement support in any sector, and to provide a useful benchmarking tool. The Standards have been developed as part of the Gold Standard Bereavement Care Project, and this article outlines the development process, and shows how the Standards can apply to the voluntary sector, National Health Services service providers, and to individual practitioners. <http://www.tandfonline.com/doi/abs/10.1080/02682621.2014.902617?queryID=%24%7BresultBean.queryID%7D>

1. 'Bereavement Care Service Standards,' 2013. http://www.cruse.org.uk/sites/default/files/default_images/pdf/Documents-and-fact-sheets/Bereavement_Care_Service_Standards.pdf

Updated 19 May 2014

[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.11.

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

Impact of the Marie Curie Cancer Care Delivering Choice Programme in Somerset and North Somerset on place of death and hospital usage: A retrospective cohort study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 16 May 2014 – The Marie Curie Cancer Care Delivering Choice Programme (DCP) aims to help palliative patients be cared for in their place of choice. In this study, new palliative care services delivered in two counties in England included end-of-life care coordination centres, an out-of-hours telephone line, and discharge in-reach nurses. The study aimed to investigate the impact of DCP on place of death and hospital usage (emergency department (ED) and admissions). Those using Delivering Choice were at least 30% less likely to die in hospital or have an emergency hospital admission or ED visit in the last 30 or 7 days of life than those who did not. Recipients of DCP services were less likely to die in or use hospital services. <http://spcare.bmj.com/content/early/2014/05/16/bmjspcare-2013-000645.abstract>

Definition of supportive care: Does the semantic matter?

CURRENT OPINION IN ONCOLOGY | Online – 13 May 2014 – A systematic review reveal several themes: a focus on symptom management and improvement of quality of life, and care for patients on treatments and those with advanced stage disease. These findings are consistent with a broad definition for supportive care: "the provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social, or physical needs during their diagnostic, treatment, or follow-up phases encompassing issues of health promotion and prevention, survivorship, palliation, and bereavement." http://journals.lww.com/co-oncol-ogy/Abstract/publishahead/Definition_of_supportive_care_does_the_semantic.99531.aspx

Palliative sedation for intolerable suffering

CURRENT OPINION IN ONCOLOGY | Online – 13 May 2014 – To maintain palliative sedation as a legitimate clinical procedure from any ethical or clinical point of view, it must be limited to the restricted area for which it was conceived, that is, relief from refractory suffering as deemed necessary by a patient and by an experienced palliative care team. In this way, there is no risk of associating palliative sedation with other end-of-life decisions. http://journals.lww.com/co-oncology/Abstract/publishahead/Palliative_sedation_for_intolerable_suffering.99532.aspx

Of related interest:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 14 May 2014 – **'The use of palliative sedation: A comparison of attitudes of French-speaking physicians from Quebec and Switzerland.'** The attitudes of physicians from Quebec and Switzerland toward palliative sedation, particularly regarding prognosis and type of suffering, seem similar. However, the results suggest that physicians from Quebec could be slightly more open to palliative sedation, even though most were not in favor of this practice as an answer to end-of-life existential suffering. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9262236&fulltextType=RA&fileId=S1478951514000364>

Cont. next page

Corrections & Clarifications

In "This is our last stop": Negotiating end-of-life transitions in assisted living,' published in the *Journal of Aging Studies*, 2014;30:1-13, the short-form AL was incorrectly identified as "assisted suicide" in Media Watch, 12 May 2014, #357 (p.11). The error was spotted during distribution of the weekly report and, therefore, corrected in some (but not all) copies of this issue of Media Watch.

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

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

Noted in Media Watch, 9 July 2012, #261 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 July 2012 – '**Framework for Continuous Palliative Sedation Therapy (CPST) in Canada.**' Canada does not have a standardized ethical and practice framework for continuous palliative sedation therapy. Canadian practice varies. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0498>

N.B. Recent articles on palliative or terminal sedation are noted in Media Watch, 10 February 2014, #344 (pp.10-11).

Advance directives, dementia, and withholding food and water by mouth

HASTINGS CENTER REPORT, 2014;44(3):23-37. For people who have dementia and are no longer competent ... control over the end of life is much less extensive [than with competent patients]. They may have written a clear advance directive for refusing life-saving care in specified circumstances yet subsequently find themselves living for years in severe dementia with no need for life-saving care that could be refused. Chronic progressive dementia is not itself life threatening until its very final stage. Even in jurisdictions that permit active aid-in-dying, individuals with advanced dementia are not eligible; they lack the required current competence, and they are seldom deemed terminally ill. As for the right to VSED [voluntarily stopping eating and drinking], its very name ... is seen as excluding non-competent persons. One option for ensuring that one does not live years in severe dementia is to use advance directives [AD] to withhold food and water by mouth. The driving element behind VSED is that forcing people to ingest food is as objectionable an intrusion on bodily integrity, privacy, and liberty as imposing unwanted medical treatment. <http://onlinelibrary.wiley.com/doi/10.1002/hast.313/abstract;jsessionid=A52EA696A904BF0A84E4F3D1799AF0EE.f03t01?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Commentary on 'Advance directives, dementia, and withholding food and water by mouth':

- *HASTINGS CENTER REPORT*, 2014;44(3):38-40. '**Towards a humane death with dementia.**' [The authors'] proposal is both appealing and unsettling. It is appealing because it offers some relief to people seeking to avoid the prolonged decline and extreme incapacity they have witnessed in relatives and friends with advanced dementia. But does it sufficiently protect patients? <http://onlinelibrary.wiley.com/doi/10.1002/hast.315/abstract>

Of related interest:

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2014;10(2):112-126. '**Vital conversations with family in the nursing home: Preparation for end-stage dementia care.**' Family members of persons with advanced dementia may be asked to make complex treatment decisions without having adequate knowledge regarding the risks and benefits. This study tested the effect of an intervention consisting of a face-to-face, structured conversation about end-of-life care options with family members of nursing home residents with advanced dementia. Intervention families had higher satisfaction with care than comparison families at the 6-month time point, and they were more likely to have decided on medical options listed in residents' advance directives (do not resuscitate, intubate, hospitalize) over time. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2014.906371?queryID=%24%7BresultBean.queryID%7D>

Promoting resiliency among palliative care clinicians: A pilot intervention

JOURNAL OF ALTERNATIVE & COMPLEMENTARY MEDICINE | Online – 7 May 2014 – Amongst healthcare providers, palliative care (PC) professionals face unique challenges of working with seriously ill patients and their families, and are prone to personal vulnerabilities. No intervention has been reported in looking at resilience with an interdisciplinary group of palliative care team members. Findings from this study demonstrate the feasibility of a pilot intervention targeted for the PC team, with significant decrease in perceived stress. Future studies should further examine further effects of these multimodal skill-building interventions delivered during work hours. <http://online.liebertpub.com/doi/full/10.1089/acm.2014.5270.abstract>

Staying at home: Risk, accommodation, and ethics in hospice care

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2014;16(4):200-205. Home hospice clinicians frequently care for patients who wish to remain in their homes, even when doing so poses a risk to patients' safety. This article introduces the concepts of the dignity of risk and accommodation, arguing such concepts can be used as ethical principles to help guide teams, patients and family members in developing plans of care... As regulatory requirements dictate that U.S. hospice nurses coordinate the care of home hospice patients, empowering such nurses to develop the capacity to integrate ethical decision making into their practice and engage their organization's ethics resources when struggling to balance competing care values supports sound practice. http://journals.lww.com/jhpn/Abstract/2014/06000/Staying_at_Home_Risk_Accommodation_and_Ethics.3.aspx

Deprivation of liberty and end of life: Does die with dignity mean to die free?

MÉDECINE PALLIATIVE | Online – 16 May 2014 – More than 10 years after the establishment of the law of 4 March 2002 on patients' rights and quality of health system, the application of one of its measures, suspension of sentence for medical reasons, remains poor. This arrangement should enable inmates with serious diseases to benefit from a release to be cared for and die free. The low effectiveness of the measure questioned its necessity and sufficiency to meet the goal of a dignified end of life. There are two opposing views regarding its necessity. <http://www.sciencedirect.com/science/article/pii/S1636652214000476>

N.B. French language article. The provision and delivery of end-of-life care in the prison system have been highlighted in Media Watch on a regular basis. A compilation of these articles and reports is available online at the Palliative Care Community Network website: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>.

Clarifying the concept of medical futility

NATIONAL CATHOLIC BIOETHICS QUARTERLY, 2014;14(1):39-46. The term "medical futility" was developed in the 1980s to enable physicians to withdraw life-prolonging procedures over the objections of patients or family members. Using clinical expertise, the physician determines that a particular treatment would be futile in a particular clinical situation. A futility judgment is clear cut when the procedure does not work, but a difficulty arises when a physician believes that a procedure provides too little benefit and then invokes futility. In that case, a patient might consider if the relatively small medical benefit might contribute to appropriately defined goals of treatment, and if so request "extraordinary means." This article places the concept "medical futility" in relation to the principle of ordinary and extraordinary means, clarifies the concept of futility, and explains the problem of redefining futile means to include procedures that retain some benefit. <http://ncbcenter.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,3,9;journal,1,53;linkingpublicationresults,1:119988,1>

To check or not to check: The role of checklists in children's palliative care

PALLIATIVE MEDICINE, 2014;28(6):461-462. Children's palliative care is somewhat of a paradox. It was patient-centered long before patient-centered became a popular term for funders and policymakers. It began as multidisciplinary, collaborative, and comprehensive as opposed to other areas in medicine that until recently were far from being teams based. It seeks to address the mind, body, and spirit in an era when most pediatric care is defined by 15-min intervals in which addressing the body is all that can be managed. It transcends cultures, as the death of a child is a loss that no parent would ever want to face. Yet, if children's palliative care is all of these things, why does it seem that something is holding us back? To answer this question, we often assemble a group of highly educated people to create a list of barriers. Our expert panel would likely come up with a list including lack of funding, lack of educated providers, and families' hesitancy to give up curative care for their child. There would probably be some lively debate about opioid availability, rights of the child, and symptom control. By the end of the day, it would be clear that at the heart of these barriers are two issues: 1) pediatric palliative care is usually not, or very minimally, available; and, 2) when it is available, it is a struggle to get children referred. This volume of *Palliative Medicine* includes two studies that are meant to shed light on the second issue.^{1,2} <http://pmj.sagepub.com/content/28/6/461.full>

1. 'The Paediatric Palliative Screening Scale: Further validity testing,' *Palliative Medicine*, 2014; 28(6):530-533. <http://pmj.sagepub.com/content/28/6/530.abstract>
2. 'Prognostic indicators for children and young people at the end of life: A Delphi study,' *Palliative care*, 2014;28(6):501-512. <http://pmj.sagepub.com/content/28/6/501.abstract>

Of related interest:

- *BMC PEDIATRICS* | Online – 13 May 2014 – '**When to stop?: Decision-making when children's cancer treatment is no longer curative: A mixed-method systemic review.**' There needs to be fresh impetus to more effectively and universally implement the ethics of professionalism into daily clinical practice in order to reinforce humanitarian attitudes. Ethical guidelines and regulations attempt to bring professionals together by articulating shared values. <http://www.biomedcentral.com/content/pdf/1471-2431-14-124.pdf>

Utilization and determinants of palliative care in the trauma intensive care unit: Results of a national survey

PALLIATIVE MEDICINE | Online – 12 May 2014 – Most common indicators for referral to palliative care were expected survival one week to one month, multi-system organ dysfunction >3 weeks, minimal neurologic responsiveness >1 week, and referral to hospice. There was a significant difference in frequency of utilization of palliative care when respondents had access to board-certified palliative care physicians. Although half of the respondents reported palliative care consults beneficial all or most of the time, nearly still half felt palliative care was underutilized. <http://pmj.sagepub.com/content/early/2014/05/13/0269216314534514.abstract>

Cont.



[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>

Of related interest:

- *HEALTH EXPECTATIONS* | Online – 12 May 2014 – '**Physicians' perceptions of the value of prognostic models: The benefits and risks of prognostic confidence.**' Physicians [i.e., study participants] perceive CPMs [clinical prediction models] as a potentially valuable means of increasing their prognostic confidence, communication, and explicit use of prognostic information in end-of-life EOL care. However, physicians' perceptions of CPMs also indicate a need to establish broad and consistent implementation processes to engage patients in shared decision making in EOL care, to effectively communicate uncertainty in prognostic information, and to help both patients and physicians manage uncertainty in EOL care decisions. <http://onlinelibrary.wiley.com/doi/10.1111/hex.12196/abstract;jsessionid=2F054D171A02A8D85BB1AC009A01889F.f03t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Patients', family caregivers', and professionals' perspectives on quality of palliative care: A qualitative study

PALLIATIVE MEDICINE | Online – 12 May 2014 – Four major dimensions of quality of care are deemed critical by patients, their families, and professionals [i.e., study participants]: 1) comprehensive support for the patients themselves; 2) clinical management; 3) involvement of families; and, 4) care for the imminently dying person and death. Differences exist between various stakeholders regarding perceptions of some dimensions of quality of care. Avenues for improving current quality of care indicators are identified. The study results can be used to refine or develop quality indicators that truly mirror the points of view of patients and their families and of healthcare professionals. <http://pmj.sagepub.com/content/early/2014/05/09/0269216314532154.abstract>

Of related interest:

- *BMC PALLIATIVE CARE* | Online – 14 May 2014 – '**Bereaved family member perceptions of patient-focused family-centred care during the last 30 days of life using a mortality follow-back survey: Does location matter?**' Bereaved informants were generally highly satisfied with the decedent's care during their last 30 days but variations were evident. Overall, no one location stood out as exceptionally different in terms of perceived unmet need within each of the patient-focused, family-centred care domains. Communication in various forms and family emotional and spiritual support were consistently viewed as lacking in all locations... <http://www.biomedcentral.com/content/pdf/1472-684X-13-25.pdf>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 12 May 2014 – '**Family perceptions of quality of hospice care in the nursing home.**' Twenty-eight participants ... identified three major aspects of collaboration as important to care delivery. First, the majority (67.9%) voiced concerns with knowing who (nursing home or hospice) is responsible for which aspects of patient care. Second, nearly half (42.9%) stated concern about information coordination between the nursing home and hospice. Finally, 67.9% of participants mentioned the need for hospice to advocate for high-quality care rather than their having to directly do so on behalf of their family members. The important concerns raised by bereaved family members ... have been incorporated into the revised Family Evaluation of Hospice Care, a post-death survey used to evaluate quality of hospice care. [http://www.jpsmjournal.com/article/S0885-3924\(14\)00249-8/abstract](http://www.jpsmjournal.com/article/S0885-3924(14)00249-8/abstract)
- *MORTALITY* | Online – 13 May 2014 – '**Families and the transition to specialist palliative care.**' In this study, the authors explore how medical specialists negotiated the transition to specialist palliative care with families. Their findings indicate that families fulfil important "functions" and "roles" in these delicate and emotionally laden conversations. Specialists' accounts articulated referral processes as distinctly relational moments, with families viewed as potential "resources" but also as "complications," in attempts for a "smooth" transition to end-of-life care. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2014.916258?queryID=%24%7BresultBean.queryID%7D>

Cont.

- *PALLIATIVE MEDICINE* | Online – 12 May 2014 – '**The challenges of uncertainty and inter-professional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals.**' Patients and carers expect primary care physicians to provide compassionate care, have appropriate knowledge, and play central roles in providing care. The roles of professionals are unclear to patients, carers and professionals themselves. Uncertainty of illness trajectory and lack of collaboration between health-care professionals were identified as barriers to effective care. <http://pmj.sagepub.com/content/early/2014/05/09/0269216314531999.abstract>

Advance care planning in palliative care: A systematic literature review of the contextual factors influencing its uptake 2008-2012

PALLIATIVE MEDICINE | Online – 12 May 2014 – Factors associated with greater uptake [of advance care planning] included older age, a college degree, a diagnosis of cancer, greater functional impairment, being white, greater understanding of poor prognosis and receiving or working in specialist palliative care. Barriers included having non-malignant diagnoses, having dependent children, being African American, and uncertainty about advance care planning and its legal status. Individuals' previous illness experiences, preferences and attitudes also influenced their participation. <http://pmj.sagepub.com/content/early/2014/05/12/0269216314531313.abstract>

End-of-life care in Canada

Understanding the distinct experience of rural inter-professional collaboration in developing palliative care programs

RURAL & REMOTE HEALTH | Online – 14 May 2014 – Palliative care is one component of rural generalist practice that requires interprofessional collaboration (IPC) amongst practitioners. Previous research on developing rural palliative care has created a four-phase capacity development model that included interprofessional rural palliative care teams; however, the details of rural team dynamics had not been previously explored and defined. A growing body of literature has produced models for interprofessional collaborative practice and identified core competencies required by professionals to work within these contexts. An Ontario College of Family Physicians discussion paper identifies seven essential elements for successful IPC: responsibility and accountability, coordination, communication, cooperation, assertiveness, autonomy, and mutual trust and respect. Despite the fact that IPC may be well conceptualized in the literature, evidence to support the transferability of these elements into rural health care practice or rural palliative care practice is lacking. <http://www.rrh.org.au/articles/subviewnew.asp?ArticleID=2711>

Noted in Media Watch, 1 April 2013, #299 (p.15):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 19 March 2013 – '**Among neighbors: An ethnographic account of responsibilities in rural palliative care.**' Families, healthcare providers, and administrators work together in fluid ways to support high quality palliative care in their communities. The very fluidity of these responsibilities can also work against high quality care. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8869654>

Noted in Media Watch, 14 January 2013, #288 (p.13):

- *RURAL & REMOTE HEALTH* | Online – 7 January 2013 – '**Comparing the experiences of rural and urban family caregivers of the terminally ill.**' Results of this study suggest that while there are commonalities to the caregiving experience regardless of setting, key differences also exist. Location is a factor to be considered when implementing palliative care programs and services. <http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=2250>

N.B. This issue of Media Watch (p.14) lists several articles noted in past issues of the weekly report on the provision and delivery of end-of-life care in rural areas. See also Media Watch 30 April 2012, #251 (p.8-9).

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2014;4(2):124-125. **'Palliative care and euthanasia: What is the view of the European Association for Palliative Care?'** The European Association for Palliative Care (EAPC) ... represents 46 national associations from 27 European countries and more than 50,000 healthcare workers and volunteers working within or interested in palliative care. Its area of influence includes 23 developing countries, primarily in Eastern Europe and Central Asia. One key issue facing all these people and countries – at the present time mostly in theory, but also in practice in places – is that of the relationship between palliative care and euthanasia. <http://spcare.bmj.com/content/4/2/124.extract>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/5/media-watch/>

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

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

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

Asia

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

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

Australia

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

Canada

ONTARIO | Central Regional Hospice Palliative Care Program: <http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1>

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

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.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://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>

Worth Repeating

The medical futility debate: Patient choice, physician obligation, and end-of-life care

JOURNAL OF PALLIATIVE MEDICINE, 2002;5(2):249-254. Physicians' use of the "medical futility" concept to override the treatment demands of patients or their family/surrogates is difficult to justify in principle. At the same time, patient demands for obviously futile treatments can conflict with physicians' professional obligation to do no harm to their patients. There is no clear general principle available to resolve this conflict between patient self-determination and physician autonomy; extended negotiation between patient or family/surrogates and physicians provides the only prospect for satisfactory resolution. Though such negotiation will not invariably succeed in reaching agreement, the legal system should ensure that each side has some practical measure of independent authority and power to exert against the other in order to maximize the likelihood that the negotiating process will be seriously engaged. [See listing of papers on medical futility that cite this article] <http://online.liebertpub.com/doi/abs/10.1089/109662102753641223>

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy and research tool.

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4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
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.



World hospice &
palliative care day

11 October 2014

Who Cares? We Do!

Home page: <http://www.worldday.org/>

Materials: <http://www.worldday.org/materials/>

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