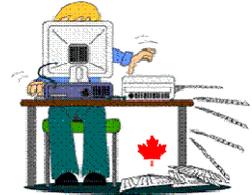


Media Watch...

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

Shared decision-making: Scroll down to [U.S.A.](#) and 'Doctor/patient communication: Who's doing the talking?' (p.4), Reuters report on studies published in *JAMA Internal Medicine*.

Canada

Elder care in Quebec

Parti Québécois pushes home care as solution to exploding medical costs

QUÉBEC | CTV News (Montreal) – 30 May 2013 – Québec Premier Pauline Marois said that health care costs for the elderly and sick will explode as of 2017, with the aging of the population. According to projections, the \$4 billion the province currently spends each year on long term care could triple in 15 years. "We cannot hide our head in the sand," said Health Minister Rejean Hebert. "There's going to be aging and an increase necessary in funding of long term care insurance." Each patient treated at home costs on average, \$30,000/year versus triple that cost for someone in hospital full time. Under the new plan, a patient staying at home would have various fees paid, including nursing, meal preparation, shopping, washing and household insurance. The money would not be paid directly to patients but to health and community groups under contract to the province. The Parti Québécois would like to implement the program as of 2014 for the elderly, in 2015 for those with physical disabilities and 2016 for adults with intellectual disabilities. <http://montreal.ctvnews.ca/pq-pushes-home-care-as-solution-to-exploding-medical-costs-1.1304573>

Noted in media Watch, 13 May 2013:

- QUÉBEC | CBC News (Montreal) – 5 May 2013 – '**Quebec announces \$15M for palliative care.**' The Parti Québécois government is injecting \$15 million dollars to improve access to palliative care in the province. Minister for Social Services Véronique Hivon said the new funding will help answer the needs of people who are sick and suffering, as well as their families. <http://www.cbc.ca/news/canada/montreal/story/2013/05/05/quebec-palliative-care-funding-parti-quebecois.html>

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>

End-of-life care in Alberta

Bed closures possible as Alberta health authority strives to trim \$220 million

ALBERTA | *The Edmonton Journal* – 29 May 2013 – A three-year health plan by Alberta's health authority that will focus more money on community care, emergency services and primary care teams could also mean the closure of hospital beds and elimination of underutilized programs. To funnel more money into priority areas, Alberta Health Services aims to find \$220 million in savings in 2013-2014 by capping hiring to current staff levels, creating more full-time nursing positions to save money on overtime costs for part-timers, cutting administrative costs and closing more operating rooms during the summer. "Every cost needs to be examined," said Stephen Lockwood, Alberta Health Services' board chairman. "Finding these savings will be tough, but pivotal, decisions that will be made to free up dollars to spend in our highest areas of priority," said Dr. Chris Eagle, CEO and president of the health authority. "Change is necessary to achieve the transformational change we're

talking about. Status quo really has no place in the health-care system. There really are no sacred cows. We are creating a system when the patients have shorter wait times for priority procedures and treatment. We're taking better care of the vulnerable and those at the end of life and youth at risk." <http://www.edmontonjournal.com/health/closures+possible+Alberta+health+authority+strives+trim+million/8450811/story.html>

Extracts from *The Edmonton Journal* article

A 10% funding increase [in community-based care] will mean more beds for continuing care, palliative and hospice services...

Eagle said no existing patient-care programs will be cut, although 26 full-time managerial, nursing and clerical positions in palliative and seniors care in Calgary are being eliminated...

Of related interest:

- ALBERTA | *The Edmonton Journal* – 1 June 2013 – **'Client concerned by Alberta Health Services plan to cut the number of home care providers.'** Public health care advocates are worried about the impact on patients when Alberta Health Services [AHS] eliminates two-thirds of the organizations providing personal home care. AHS is expected to reduce the number of contractors in this field to 10 from 32 ... to save the province more than \$18 million annually. <http://www.edmontonjournal.com/health/Alberta+Health+Services+plans+number+home+care+providers/8466649/story.html>

Noted in Media Watch, 20 May 2013:

- ALBERTA | *The Calgary Herald* (OpEd) – 16 May 2013 – **'Cuts to palliative care nurses a callous route to cost savings.'** If Alberta Health Services is going to lay off 24 registered nurses who do palliative home care, it should stop insulting the public's intelligence by insisting ... that palliative care will continue as it currently does. Those 24 nurses represent practically half of the 50 in the program; it is unrealistic to expect anyone to believe the same care can be delivered by half the current team, but with the addition of some licensed practical nurses. <http://www.calgaryherald.com/opinion/Editorial+Cuts+palliative+care+nurses+callous+route+cost+savings/8396823/story.html>

 World hospice &
palliative care day
Voices for hospices 2015

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

12 October 2013

Free-standing residential hospices

Hospice care gap in Nova Scotia

NOVA SCOTIA | Hospice Society of Greater Halifax – 28 May 2013 – With Halifax Regional Municipality being the largest health district in Canada without a residential hospice, the Hospice Society of Greater Halifax is calling on Nova Scotians to join together to help advance the cause of residential hospice in Nova Scotia. Currently Nova Scotians must choose to die either in the hospital – or at home. Establishing residential hospice care will provide better care and ultimately help reduce health care costs for Nova Scotians. The average *per diem* cost for an acute care bed in Capital Health is approximately \$1000.00/day. The cost of delivering palliative care in a residential hospice bed has been shown to be significantly less than in acute care, with an average cost of \$450.00/day. <http://www.newswire.ca/en/story/1173183/hospice-care-gap-in-nova-scotia>

Noted in Media Watch, 3 October 2012:

- NOVA SCOTIA | *Metro Halifax* – 27 September 2011 – '**Non-profits unite over end-of-life care.**' Sixteen not-for-profit organizations joined forces to form the Quality End of Life Care Coalition of Nova Scotia in an attempt to help shape public policy and to raise awareness concerning end-of-life care in the province. <http://www.metronews.ca/halifax/local/article/980703--non-profits-unite-over-end-of-life-care>

U.S.A.

The family caregiver turns pro

NEW YORK TIMES | Online – 31 May 2013 – Everyone who thinks about the so-called work force problem for the elderly can see big trouble coming. Who's going to provide care for the growing number of old people who, even with the enormous efforts from family members, will most likely need more help? Or who don't have families? And, who prefer, overwhelmingly to stay in their homes? For now, the workers who take on home care represent a polyglot group. They work independently or through agencies; they are largely underpaid and lack benefits; they do a tough job and have high injury rates; they run the gamut from inadequately trained to professionally skilled. Already, we don't have enough of them. That we are still waiting to learn if the Obama administration

will honor its pledge and at least provide the same wage and hour protections as other workers handily demonstrates the problem. These low-wage aides, most of whom are women, lack economic or political clout. <http://newoldage.blogs.nytimes.com/2013/05/31/the-family-caregiver-turns-pro/?ref=health>

Specialist Publications

'The positive aspects of caregiving for cancer patients: A critical review of the literature and directions for future research' (p.8), in *Psycho-Oncology*.

Hospice bill proves good common-sense legislation still exists in Wyoming

WYOMING | *The Star Tribune* (Casper) – 29 May 2013 – Medicaid is the government health program for people with low incomes. The program, however, does not cover room and board for hospice care, and the result was an end-of-life gap for too many residents. A new bill allows the state to cover half of the cost of hospice room and board for Medicaid patients. It becomes law in Wyoming 1 July. http://trib.com/news/opinion/editorial/hospice-bill-proves-good-common-sense-legislation-still-exists-in/article_06ee1acb-fe38-523d-8b97-8f7194685119.html

Shared decision-making

Doctor/patient communication: Who's doing the talking?

REUTERS | Online – 27 May 2013 – There's room – and need – for improvement in the discussions between doctor and patient that go into medical decision-making, according to [recently published] research.¹ In four studies and a commentary, the authors look at various aspects of doctors' dialogue with patients about prognoses, options and treatment preferences and find little consistency. And though not all patients want the responsibility of making treatment decisions, medical organizations have long promoted the idea of patient-centered care through shared decision-making, and the Affordable Care & Patient Protection Act that goes into effect next year incorporates the idea into law. What's more, "When physicians reach out and communicate to patients that their

views are welcome, patients really like that a lot," said Floyd Fowler, a senior advisor for the Informed Medical Decisions Foundation in Boston. But research in the past decade showed that patients with common medical conditions were not being adequately informed about their treatment options. <http://medcitynews.com/2013/05/doctorpatient-communication-whos-doing-the-talking/>

Specialist Publications

'When previously expressed wishes conflict with best interests' (p.11), in *JAMA Internal Medicine*.

1. *JAMA Internal Medicine*, 27 May 2013:
 - a. 'How patient centered are medical decisions? Results of a national survey.' Discussions about common tests, medications, and procedures as reported by patients do not reflect a high level of shared decision making. <http://archinte.jamanetwork.com/article.aspx?articleid=1691770>
 - b. 'Relationship between the prognostic expectations of seriously ill patients undergoing hemodialysis and their nephrologists.' Patients' expectations about 1-year survival are more accurate than those of their nephrologists, but their longer-term survival expectations dramatically overestimated even their 2-year survival rates. <http://archinte.jamanetwork.com/article.aspx?articleid=1691764>
 - c. 'Association of patient preferences for participation in decision making with length of stay and costs among hospitalized patients.' Patient preference to participate in decision making concerning their care may be associated with increased resource utilization among hospitalized patients. <http://archinte.jamanetwork.com/article.aspx?articleid=1691765>

Invited commentary: <http://archinte.jamanetwork.com/article.aspx?articleid=1691772>
 - d. 'Decision-making preferences among patients with an acute myocardial infarction.' Despite numerous calls for greater participation by patients in the medical decision-making process, shared decision-making is not yet integrated into routine medical care, perhaps because of a perception that patients wish to defer to their physicians. <http://archinte.jamanetwork.com/article.aspx?articleid=1691767>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MAINE PUBLIC BROADCASTING NETWORK | Online – 31 May 2013 – **'Maine House rejects assisted suicide bill.'** Maine lawmakers declined to follow in the footsteps of Vermont, rejecting a bill that would have allowed physician-assisted suicide in Maine. After nearly an hour of debate ... lawmakers rejected the bill, 95-43. The measure now moves to the Senate. <http://www.mpbn.net/News/MaineHeadlineNews/tabid/968/ctl/ViewItem/mid/3479/ItemId/28238/Default.aspx>

Cont.

- GALLUP POLITICS | Online – 29 May 2013 – **'U.S. support for euthanasia hinges on how it's described.'** In the same month that Vermont became the fourth state to legalize physician-assisted suicide, a May 2-7 Gallup survey finds 70% of Americans in favor of allowing doctors to hasten a terminally ill patient's death when the matter is described as allowing doctors to "end the patient's life by some painless means." At the same time, far fewer – 51% – support it when the process is described as doctors helping a patient "commit suicide." Gallup's question with the softer description of euthanasia – calling it "ending a patient's life by some painless means" – also specifies that both the patient and his or her family requested it. The "suicide" version says the patient requests assistance from a doctor, without referencing other family members. <http://www.gallup.com/poll/162815/support-euthanasia-hinges-described.aspx>

N.B. The authors of 'Confusion between euthanasia and other end-of-life decisions: Influences on public opinion polls,' *Canadian Journal of Public Health*, 2007;98(3):235-238, observed that "public opinion polls on euthanasia" should be interpreted in the light of the wording of the question. "Education of the population concerning euthanasia," and other end-of-life decisions, would be an important prerequisite to engage in public debate concerning the legalization of euthanasia. <http://journal.cpha.ca/index.php/cjph/article/view/820/820>

International

Doctors call for global consensus on diagnosis of death

EUROPE | BBC News (U.K.) – 2 June 2013 – There needs to be international agreement on when and how death is diagnosed, two leading doctors say. Improvements in technology mean the line between life and death is less clear. They call for precise guidelines and more research to prevent the rare occasions when people are pronounced dead but are later found to be alive. The WHO has begun work to develop a global consensus. In the majority of cases in hospitals, people are pronounced dead only after doctors have examined their heart, lungs and responsiveness, determining there are no longer any heart and breath sounds and no obvious reaction to the outside world. <http://www.bbc.co.uk/news/health-22730360>

Specialist Publications

'Atlas of palliative care in Europe 2013' (p.10), posted by the European Association for Palliative Care.

'Death, dying and bereavement? Nordic perspectives' (p.12), in *Mortality*.

Crisis deepens over children's hospice care

U.K. (SCOTLAND) | *The Herald* (Edinburgh) – 31 May 2013 – Members of the Scottish Parliament's cross-party group on muscular dystrophy (MD) are to request Health Secretary Alex Neil to meet with them to discuss a crisis in respite services for young adults. The Children's Hospice Association Scotland [CHAS] is imposing an age limit on those using its services. Members of staff from Robin House ... confirmed at the cross-party group's meeting this week that in three years anyone over 21 will no longer be able to use the respite service, which is aimed at children. Parents of young adults affected by the muscle-wasting disease expressed concern and alarm at the short timescale for finding replacement services, given that adult hospice services are mainly set up to work with elderly people. <http://www.heraldscotland.com/news/health/crisis-deepens-over-childrens-hospice-care.21216242>

Noted in Media Watch, 13 May 2013:

- U.K. (SCOTLAND) | *The Herald* (Edinburgh) – 10 May 2013 – **'Hospice charity sets age limit on services for young people.'** CHAS chief executive Maria McGill ... said there was a lack of suitable services for people aged 25-45, with adult hospice services set up largely to cater for much older adults suffering from cancer and other terminal illnesses. <http://www.heraldscotland.com/news/health/hospice-charity-sets-age-limit-on-services-for-young-people.21041823>

The cost of funerals around the world

MONEY MARKET INTERNATIONAL | Online – 29 May 2013 – Around the world, the cost of funerals is on the rise. In some countries, private home wakes have been replaced by more formalised morgue wakes – adding to the costs. Flowers, plots of land, car-hire, and administrative costs have all risen in recent years. A full service funeral in the U.K. and in Spain, for instance, includes transportation by hearse to the cemetery and, depending on the case, wreaths, obituaries and cremation – if it has been agreed. And the U.K. ranks the highest around Europe with its funeral costs. Spain is in the middle price-bracket; while in Latin America, the costs are scaled to salary and cost of living. <http://www.money-marketuk.com/index.php/news/3030-the-cost-of-funerals-around-the-world>

Hospice facing "decline in real terms" in National Health Service funding

U.K. (ENGLAND) | *The Welwyn Hatfield Times* – 29 May 2013 – Bosses at Isabel Hospice ... are facing up to a "real terms decline" in funding – which means they need to raise even more this year than in previous years. The charity's chief executive, Nigel Furlong, said running costs are set to increase by a whopping £63,000 – yet its grant from the National Health Service has gone up by just £5,000. The news was released as hospice chiefs approved their annual budget. <http://www.whtimes.co.uk/news/hospice-facing-decline-in-real-terms-in-nhs-funding-1-2214120>

Elderly care homes: Wales quality review by commissioner

U.K. (WALES) | BBC News – 28 May 2013 – Older people in care homes are to be asked about the quality of care they receive in a new review. Sarah Rochira, the older people's commissioner for Wales [Comisiynydd Pobl Hŷn Cymru], says she will use her legal powers to carry out the study. It will involve speaking to older people, their families and carers to ensure more consistency of services. The Care & Social Services Inspectorate Wales has welcomed the move. <http://www.bbc.co.uk/news/uk-wales-22679982>

Elder care in Europe

Dutch district nurses rediscover "complete care" role

THE NETHERLANDS | BBC News (U.K.) – 27 May 2013 – The idea here is that in a single un-hurried visit a highly trained nurse can accomplish much more than several health and homecare workers popping in to do their allotted tasks. So the costs per hour may be higher, but patients need thirty-to-forty per cent fewer hours of care. Cora Duinkerken says it's a great way to work. "We choose to work maybe under our level but with that we can give the client complete care. That's better for the client, but it also makes our job a lot more diverse. You get a much closer relationship with the client because you spend a lot more time with them so they eventually will share a lot more with you." The nurses work in teams of 10, each serving a neighbourhood of about 10,000 people. The teams run themselves – there are no managers. They are available round the clock and – working closely with GPs – they organise all the supporting care, drawing in families, friends, and volunteers. They see themselves as community-builders. In Amsterdam, Buurtzorg nurses run a weekly radio show – Radio Steunkous – which translates as radio "support-stocking." It offers health advice, provides information on local services, and puts people in touch with each other. <http://www.bbc.co.uk/news/health-22450482>

Noted in Media Watch, 27 May 2013:

- *NURSING ETHICS* | Online – 23 May 2013 – "**Busyness" and the preclusion of quality palliative district nursing care.** Ethical care is beginning to be recognised as care that accounts for the views of those at the receiving end of care. However, in the context of palliative and supportive district nursing care, the patients' and their carers' views are seldom heard. <http://nej.sagepub.com/content/early/2013/05/16/0969733013485109.abstract>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IRELAND | *The Irish Times* (Dublin) – 29 May 2013 – **'Kenny will not legislate for assisted suicide.'** Taoiseach [Prime Minister] Enda Kenny has rejected calls to bring in new laws allowing assisted suicide. Tom Curran, partner of terminally ill multiple sclerosis sufferer Marie Fleming attended the Dáil [lower house of the Irish Parliament], as the couple continue their fight for her right to die after being refused by the courts. "By any standards this is an extraordinary case involving an extraordinary woman," Mr. Kenny said. "I believe that if this house were asked to find words to adequately describe the impeccable courage and dignity and competence of Ms. Fleming it would probably be rendered mute." Independent TD [Teachta Dála] John Halligan called on the Taoiseach to legislate for assisted suicide with necessary safeguards and to allow for the contentious issue to be debated in the Dáil. <http://www.irishtimes.com/news/politics/kenny-will-not-legislate-for-assisted-suicide-1.1409881>

Noted in Media Watch, 6 May 2013:

- IRELAND | *The Independent* (Dublin) – 29 April 2013 – **'Marie Fleming loses Supreme Court right-to-die case.'** A woman in the final stages of Multiple Sclerosis has lost her landmark challenge to Ireland's legal ban on assisted suicide. A full, seven-judge Supreme Court gave its ruling in the so called "right to die" action brought by Ms. [Marie] Fleming who wants to be helped to end her life at a time of her choosing. <http://www.independent.ie/irish-news/courts/marie-fleming-loses-supreme-court-righttodie-case-29228686.html>

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

Caregiver evaluation of the ACTIVE intervention: "It was like we were sitting at the table with everyone"

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 May 2013 – This study evaluates participant experience of the ACTIVE (assessing caregivers for team intervention via video encounters) intervention, designed to use web conferencing technology to overcome the barriers of participation in development and review of individual care plans. Caregivers involved in the intervention reported positive relationships with the hospice staff, felt involved in decision making, and got answers to their questions. Furthermore they reported staff was responsive to their needs and that participation increased their confidence, trust in the team, and provided a feeling of not being alone if they needed help. Challenges included issues with the technology, a feeling of being rushed and a frustration when they did not feel included or involved. Suggestions for improving the intervention included a more frequent meeting time, a need to train hospice staff how to conduct web-based interactions, and suggestions for additional information for caregivers. <http://ajh.sagepub.com/content/early/2013/05/23/1049909113490823.abstract>

Effets sur les soignants de la douleur et de la souffrance des patients

(Effects on caregivers of patients' psychological or physical pain)

MÉDECINE PALLIATIVE | Online – 29 May 2013 – Caregivers generally manage to take on patients' pain and suffering or to unconsciously set up defense mechanisms to protect themselves. But when they begin to feel powerless, they can become subject to trauma, especially if this sentiment persists. The theoretical articulation between powerlessness and the similar concept of "Hilflosigkeit" is heuristic. This latter teaches us that, in these situations, the existence of a third party, foreign to the staggering situations experienced by the caregivers is important. This person will allow the staff to reflect on what they are going through. This is the goal of supervision groups. A place in which to deposit emotions, they also provide an environment to work on counter-transference, to identify the effects of caregivers' ego ideal and to elaborate into thought raw emotional experiences. <http://www.sciencedirect.com/science/article/pii/S1636652213000330>

Cont.

Of related interest:

- *PSYCHO-ONCOLOGY* | Online – 28 May 2013 – **'The positive aspects of caregiving for cancer patients: A critical review of the literature and directions for future research.'** A total of 35 articles were identified. The focus of these studies and their results were described on the basis of the Conceptual Framework of the Positive Aspects of Caregiving. Findings revealed spousal caregivers for cancer patients experienced various positive aspects of caregiving, such as an enhanced relationship with the care-receiver, the feeling of being rewarded, a sense of personal growth, and a perception of personal satisfaction. Daily enrichment events and self-efficacy on the part of the caregivers were identified as the determining factors in the positive aspects of caregiving. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3311/abstract>

Harnessing complex emergent metaphors for effective communication in palliative care: A multimodal perceptual analysis of hospice patients' reports of transcendence experiences

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 May 2013 – Terminally ill patients can have unexpected, enigmatic, and profound cognitive shifts that significantly alter their perception of themselves, thereby eliminating their fear of death and dying. However, there are no systematic studies into these remarkable yet ineffable transcendence experiences. They therefore remain easily overlooked or viewed as isolated anomalies and therefore excluded from quality-of-life patient considerations. The authors use a multimodal methodology for identifying the prevalence and thematic properties of complex emergent metaphors patients use to report these experiences. Although previous research has pioneered the importance of understanding conventional or primary metaphors at the end of life, their findings indicate the considerable potential of more complex metaphors for reducing barriers to effective communication in palliative care. <http://ajh.sagepub.com/content/early/2013/05/23/1049909113490821.abstract>

Noted in Media Watch, 30 July 2012:

- *PALLIATIVE MEDICINE* | Online – 24 July 2012 – **'The patient's use of metaphor within a palliative care setting: Theory, function and efficacy. A narrative literature review.'** The results suggest that engaging with patients at the metaphoric level enables them to create new ways of viewing their situation and opens up the possibilities of new coping strategies. <http://pmj.sagepub.com/content/early/2012/07/20/0269216312451948.abstract>

Noted in Media Watch (under 'Worth Repeating'), 1 February 2012:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 1998;15(5):282-284. **'Communicating with metaphor: A dance of many veils.'** The creative and judicious use of metaphor provides health care practitioners with many veils – veils that shield the dying from the glare of their prognosis, veils particularly valuable and suited in communicating with our palliative patient population. <http://ajh.sagepub.com/cgi/content/abstract/15/5/282>

Doctors increasingly shut out of hospitals' patient experience efforts

AMERICAN MEDICAL NEWS | Online – 27 May 2013 – As hospital and health systems examine how to improve the patient experience, one prominent constituency increasingly is not being considered to lead the effort: physicians. Only 3% of executives in a survey ... said physicians or other clinicians held primary responsibility and accountability for addressing the patient experience. Even fewer, 1%, said chief medical officers were in charge, while 14% said chief nursing officers were. The most common form of patient experience leadership was committee, cited by 26% of executives, followed by a dedicated patient experience executive, cited by 22%. <http://www.amednews.com/article/20130527/business/130529966/4/>

[Media Watch Online](#)

Media Watch is posted on several websites that serve the hospice and palliative care community-at-large. See a complete listing on p.14.

End-of-life care in New Zealand

Doctors' willingness to give honest answers about end-of-life practices: A cross-sectional study

BMJ OPEN | Online – 22 May 2013 – Many New Zealand doctors were willing to give honest answers to questions about end-of-life practices, particularly if anonymity was guaranteed; others, however, expressed doubts or indicated that they would not be willing to provide honest answers to questions of this sort. <http://bmjopen.bmj.com/content/3/5/e002598.abstract>

Paediatric palliative care in the U.K.

Volunteer activity in specialist paediatric palliative care: A national survey

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 31 May 2013 – This is the most detailed national survey of volunteer activity in palliative care services for children and young people to date. It highlights the range and depth of volunteers' contribution to specialist paediatric palliative care services and will help to provide a basis for future research, which could inform expansion of volunteers' roles. <http://spcare.bmj.com/content/early/2013/05/31/bmjspcare-2012-000355.abstract>

When does life-sustaining treatment become futile?

BRITISH JOURNAL OF NURSING, 2013;22(10):590-591. The law has long recognised that providing continued life-sustaining treatment to very sick and critically ill patients may be futile. The courts have consistently rejected an absolutist approach to care and treatment that requires doctors and nurses to continue with futile treatment right up to the point of death. If it is no longer in the best interests of the patient to receive treatment, then even life-sustaining treatment may be lawfully withdrawn. It is essential that nurses know when care and treatment becomes futile to ensure they are acting lawfully if a decision is taken to withdraw that care and treatment. In this article the author considers the Court of Appeal's recent test for determining when treatment becomes futile and its impact on nursing practice. http://www.internurse.com/cgi-bin/go.pl/library/article.cgi?uid=98755;article=BJN_22_10_590_591;format=pdf

Of related interest:

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



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>

Atlas of palliative care in Europe 2013

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online – 29 May 2013 – The aim of this study is to provide an updated, reliable and comprehensive analysis on the development of palliative care within each European country in order to generate and disseminate an "evidence base" of clear and accessible research-based information concerning the current provision of the discipline across the WHO European region ... [to] ... provide governments and policymakers with a new understanding of the development of programs to promote palliative care ... and that this will, in turn, have a positive impact upon providers of palliative care services in a direct, practical way through an improvement in the development of policy and practice and future service design. http://issuu.com/universidaddenavarra/docs/atlas_europa_full_edition

Understanding and coping with diversity in healthcare

HEALTH CARE ANALYSIS | Online – 30 May 2013 – In the healthcare sector, race, ethnicity and religion have become an increasingly important factor in terms of patient care due to an increasingly diverse population. Health agencies at a national and local level produce a number of guides to raise awareness of cultural issues among healthcare professionals and hospitals may implement additional non-medical services, such as the provision of specific types of food and dress to patients or the hiring of chaplains, to accommodate the needs of patients with religious requirements. However, in an attempt to address the spiritual, cultural and religious needs of patients healthcare providers often assume that ethnic minority groups are homogenous blocks of people with similar needs and fail to recognize that a diverse range of views and practices exist within specific groups themselves. This paper describes the example of the Sikh community and the provision of palliative care in hospitals and hospices. Although, the majority of patients classifying

themselves as Sikhs have a shared language and history, they can also be divided on a number of lines such as caste affiliation, degree of assimilation in the west, educational level and whether baptized or not, all of which influence their beliefs and practices and hence impact on their needs... <http://link.springer.com/article/10.1007/s10728-013-0249-0>

Extract from *Health Care Analysis* article

Given that it is unfeasible for health providers to have knowledge of the multitude of views within specific religious and ethnic communities and accounting for the tight fiscal constraints of healthcare budgets, this paper concludes by raising the question whether healthcare providers should step away from catering for religious and cultural needs that do not directly affect treatment outcomes, and instead put the onus on individual communities to provide resources to meet spiritual, cultural and religious needs of patients.

Living and dying: Responsibility for end-of-life care in care homes without on-site nursing provision – A prospective study

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 29 May 2013 – Review of care home notes demonstrated that residents had a wide range of healthcare problems. Length of time in the care homes, functional ability or episodes of ill-health were not necessarily meaningful indicators to staff that a resident was about to die. General practitioner and district nursing services provided a frequent but episodic service to individual residents. There were two recurring themes that affected how staff engaged with the process of advance care planning with residents; "talking about dying" and "integrating living and dying." All [study] participants stated that they were committed to providing end-of-life care and supporting residents to die in the care home, if wanted. However, the process was complicated by an ongoing lack of clarity about roles and responsibilities in providing end-of-life care, doubts from care home and primary healthcare staff about their capacity to work together when residents' trajectories to death were unclear. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12055/abstract>

Training in cardiology: Is end-of-life care being addressed?

HEART, 2013;99(2):A11. This survey shows that despite being part of the national curriculum for training in cardiology since 2010, trainees' level of confidence in delivering end of life care in advanced heart failure and discussing prognosis in patients with an implantable cardioverter-defibrillator is poor. Specific training in end-of-life care remains a neglected part of the curriculum; this could be rectified by joint training with palliative care and more formal assessment of these skills. http://heart.bmj.com/content/99/suppl_2/A11.2.abstract

Challenges and responses in providing palliative care for people living with HIV/AIDS

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2013;19(5):218-225. This article synthesises a body of literature to highlight several clinical and systematic challenges that should be addressed in implementing a palliative approach to care for HIV/AIDS patients. They involve pain and symptom management, health-care providers' perceptions of HIV/AIDS, patients' beliefs about palliative care, variability in informal care resources, socioeconomic and demographic determinants of palliative care, and difficulties in evaluating the effectiveness of palliative care. To inform current practice in the palliative care domain, responses to the identified challenges are discussed. A disease stage-specific model is presented... http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=98802;article=IJPN_19_5_218_225

Advance directives

When previously expressed wishes conflict with best interests

JAMA INTERNAL MEDICINE | Online – 27 May 2013 – Rising use of advance directives has made surrogate decision making both easier and harder. In many cases, these directives help guide decision making for patients who have lost decision-making capacity. In some cases, however, directives may conflict with what physicians or surrogates view as what is in the patient's best interest. These conflicts can place substantial emotional and moral burdens on physicians and surrogates, and there is little practical guidance for how to address them. The authors propose a 5-question framework for untangling the conflict between advance directives and best interests of a patient with a surrogate decision maker: 1) Is the clinical situation an emergency? 2) In view of the patient's values and goals, how likely is it that the benefits of the intervention will outweigh the burdens? 3) How well does the advance directive fit the situation at hand? 4) How much leeway did the patient provide the surrogate for overriding the advance directive? 5) How well does the surrogate represent the patient's best interests? The authors use two clinical cases with contrasting outcomes to demonstrate how this framework can help resolve common dilemmas. <http://archinte.jamanetwork.com/article.aspx?articleid=1691766>

Of related interest:

- *CONTEMPORARY NURSE* | Online – 26 March 2013 – **'Honouring the wishes of a dying patient: From intensive care to home with palliative care.'** The challenge for doctors is to maintain open communication and shared decision making with patients' and family members at this sensitive time. This can be challenging due to the culture of ICU which focuses on saving lives rather than palliation. Facilitating discussions for terminally ill patients in ICU may enhance their end of life care and assist patients to die in an environment of their choice such as their home. <http://www.contemporarynurse.com/archives/vol/45/issue/2/article/5158/honouring-the-wishes-of-a-dying-patient>

Death, dying and bereavement? Nordic perspectives

MORTALITY, 2013;18(2):109-115. 'Introduction to the Nordic issue of *Mortality*.' The Nordic countries – Norway, Sweden, Denmark, Finland and Iceland – are a culture, geographical and historical entity. The countries vary widely in their own perspectives, but to an outsider, they may seem almost identical. The welfare state, cold climate, reticent people, gender equality, Lutheran confession and linguistic similarities give an impress of unit. Indeed, it would not be far-fetched to think that the Nordic countries have a lot in common when it comes to the culture on death and death rituals. This special issue presents some viewpoints on death in the Nordic countries. Journal contents page: <http://www.tandfonline.com/toc/cmrt20/current>

Preferred place of death for children and young people with life-limiting and life-threatening conditions: A systematic review of the literature and recommendations for future inquiry and policy

PALLIATIVE MEDICINE | Online – 31 May 2013 – Nine studies were included from five countries. Six reported a majority of parents ... expressing preference for death at home. Other studies differed significantly in their findings; one reporting 35.1% and another 0% preferring death at home. Some parents did not express a preference. Six of the studies included only parents of children who died from cancer while being treated at tertiary centres that offered palliative care services. Such results cannot be generalised to the population of all life-limiting and life-threatening illnesses. Furthermore, methods of the studies failed to accommodate the full range and dynamic character of preference. The evidence base for current policies that stress the need to increase home death rates for children and young people with life-limiting and life-threatening conditions is inadequate. <http://pmj.sagepub.com/content/early/2013/05/31/0269216313483186.abstract>

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Media Watch: Editorial Practice

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

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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

Something Missed or Overlooked?

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

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 27 May 2013 – **'Preferred place of death for patients referred to a specialist palliative care service.'** Most patients in a specialist palliative care setting are willing to express a PPD [preferred place of death]. Preferences differ for patients who had never been admitted as hospice inpatients from those who have had at least one inpatient stay. Routine and ongoing assessment of PPD are recommended... <http://spcare.bmj.com/content/early/2013/05/27/bmjspcare-2012-000338.abstract>

Representative sample of articles in preferred place of death noted in Media Watch:

- *PALLIATIVE MEDICINE* | Online – 22 May 2013 – **'Dying at home – is it better: A narrative appraisal of the state of the science.'** Meeting patients' preferences and creating home-like environments has been a major concern for hospice and palliative care since its inception. The authors call for further analyses of variations in place of care and place of death and robust studies on how patients and families formulate and change preferences over time. <http://pmj.sagepub.com/content/early/2013/05/22/0269216313487940.abstract>
- *JOURNAL OF HOSPITAL MEDICINE* | Online – 25 February 2013 – **'Where do you want to spend your last days of life? Low concordance between preferred and actual site of death among hospitalized adults.'** The overwhelming majority of persons state they would prefer to die at home. Recent findings suggest most people will die in an institutional setting. <http://onlinelibrary.wiley.com/doi/10.1002/jhm.2018/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false>
- *BMC PALLIATIVE CARE* | Online – 4 November 2011 – **'Documentation of end-of-life care and preferred place to die discussions in the final weeks of life.'** While there was evidence that discussions relating to end of life care and preferred place to die had taken place in around half of the audited case notes, there appeared to be a lack of a systematic approach to the recording of discussions with patients or carers about these kind of issues. <http://www.biomedcentral.com/content/pdf/1472-684x-10-18.pdf>
- *PALLIATIVE MEDICINE* | Online – 12 January 2011 – **'Achieving the preferred place of care for hospitalized patients at the end of life.'** Data highlights the need to distinguish between preferred place of care [PPC] and preferred place of death. Patients' wishes regarding PPC change as death approaches. A greater number of patients wished to die in hospital than was expected. <http://pmj.sagepub.com/content/early/2010/12/01/0269216310387459.abstract>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 January 2010 – **'Factors associated with congruence between preferred and actual place of death.'** Congruence between preferred and actual place of death may be an essential component in terminal care. Most patients prefer a home death, but many patients do not die in their preferred location. [http://www.jpmsjournal.com/article/S0885-3924\(09\)01137-3/abstract](http://www.jpmsjournal.com/article/S0885-3924(09)01137-3/abstract)

GPs avoiding Liverpool Care Pathway "due to adverse publicity"

PULSE (U.K.) | Online – 30 May 2013 – Negative publicity surrounding The Liverpool Care Pathway [LCP] is causing some GPs to avoid using it in patients nearing the end of their lives, the Royal College of General Practitioners has told a Government review into the pathway. The college said that the controversy surrounding the palliative care pathway in the press meant it has become a "barrier" to communication with patients for some GPs and is often avoided. The LCP is recommended by NICE [the National Institute for Health & Care Excellence] and the Department of Health as the best practice model for end-of-life care, and it is designed to improve the care of the patient in the last hours or days of life. Last year numerous media stories claimed elderly patients had been refused food and water to speed up death and that neither they, nor relatives have been told doctors consider their case to be terminal. [National Health Service] Trusts were accused of being incentivised to put elderly patients on the pathway to cut costs. <http://www.pulsetoday.co.uk/clinical/therapy-areas/pain-relief/gps-avoiding-liverpool-care-pathway-due-to-adverse-publicity-says-rcgp/20003120.article#.UadUGNJwomY>

Cont.

Representative sample of recent articles on The Liverpool Care Pathway noted in Media Watch:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2013;20(3):109. '**Controversy around The Liverpool Care Pathway – the fundamental issue is consent.**' The furore around the Liverpool Care Pathway (LCP) continues. The publicity about it has been noxious. Despite the fact that over 20 reputable organisations have pledged their support to the LCP, the media appear to persist in the publication of misconceptions and inaccurate facts. And the public remains concerned and confused. How has it all gone so horribly wrong? Why has it come to this?

N.B. Access to the *European Journal of Palliative Care* requires a subscription. Contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2013&Edition=47 4. The Liverpool Care Pathway is currently subject to a review commissioned by the Department of Health, England (<https://www.gov.uk/government/news/review-of-liverpool-care-pathway-outlined>).
- *BRITISH MEDICAL JOURNAL* | Online – 7 March 2013 - '**The Liverpool Care Pathway [LCP]: What do specialists think?**' The motivation and idea behind optimal palliation during the final days of a person's life is an acceptable concept to most health workers. It makes good medical sense and is the end of the continuum of good palliative care or even acute care. <http://www.bmj.com/content/346/bmj.f1184/rr/634874>

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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.hnhbpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpconnection.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)

- U.K. (ENGLAND) | Department of Health – 5 March, 2013 – **'Liverpool Care Pathway independent review: First meeting of the review panel.'** The panel appointed to review the use and experience of the Liverpool Care Pathway for Dying Patients, chaired by Baroness Julia Neuberger, met for the first time 18 February 2013. At that meeting the panel acknowledged the serious nature of this review and committed to giving full consideration to all the evidence submitted to it. <http://www.dh.gov.uk/health/2013/03/lcp-review-meeting/>

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