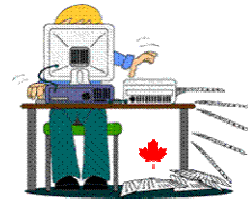


Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

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

Compiled & Annotated by Barry R. Ashpole

Missed opportunity? Scroll down to [Specialist Publications](#) and 'Leveraging external resources to grow and sustain your palliative care program: A call to action' (p.10), published in the *Journal of Palliative Medicine*.

Canada

Struggling against expectations

Plain speaking at the end of life

NOVA SCOTIA | *New York Times* – 14 December 2011 – Dr. Stephen Workman, an internist at the Queen Elizabeth II Health Sciences Center in Halifax, Nova Scotia, takes exception to the language physicians use with patients near the end of life. In one of his recent publications,¹ he called language the most important tool health professionals have to improve the care of dying patients. I wanted to know more about his ideas, so we spoke by phone. **Q.** You've decried the way hospitals and their staffs treat the dying, calling it "an avoidable tragedy." Why does that happen? **A.** The system is geared for intervention. The narrative of medicine, the stories doctors love to tell and patients love to hear, is that we can identify the problem and fix it. It's hard to say when that's no longer true, but there comes a time for all of us. If physicians challenge their belief that they can cure everyone, they will identify a lot of people who are dying or at risk of dying. And generally care gets pretty rational after that. Once we recognize that someone is dying and that dying people have a claim upon us, things usually become more humane and compassionate.

<http://newoldage.blogs.nytimes.com/2011/12/14/plain-speaking-at-the-end-of-life/>

1. 'Never say die? – as treatments fail doctors' words must not,' *International Journal of Clinical Practice*, 2011;65(2):117-119. <http://onlinelibrary.wiley.com/doi/10.1111/j.1742-1241.2010.02585.x/pdf>

From Media Watch dated 30 May 2011:

- *JOURNAL OF LANGUAGE & SOCIAL PSYCHOLOGY*, 2011;30(2):177-192. **'Hope and the act of informed dialogue: A delicate balance at end of life.'** The guidelines provided to me in the past research with which I was familiar, as well as my personal experiences regarding end-of-life discussion with family and friends, did not prepare me well to handle the dialectical tensions between maintaining hope and open discussion of end of life in this situation. In this article, I focus on an examination of the research on hope at end of life and try to reconcile it with the concomitant need for acknowledgment of impending terminality and the communication that should accompany this. <http://jls.sagepub.com/content/30/2/177.abstract>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *GLOBE & MAIL* | Online article – 16 December 2011 – **'Haunting right-to-die case weighs on judges' minds, 18 years on.'** Jack Major can still see the silent ranks of disabled people, their wheelchairs ringing the Supreme Court of Canada as a courtroom full of lawyers debated the assisted suicide law in 1993. "It was a haunting type of case," said Mr. Major, who was the Supreme Court judge whose vote tipped the balance in a 5-4 decision affirming the law. Eighteen years later, the polarizing question is heading back to the top court. A Vancouver judge finished hearing a test case on Friday launched by Gloria Taylor, a terminally ill B.C. woman. It was the first step of a journey that will ultimately compel the top court to grapple anew with whether the terminally ill can obtain help to end their lives. http://www.theglobeandmail.com/life/health/end-of-life/haunting-right-to-die-case-weighs-on-judges-minds-18-years-on/article2274635/?utm_medium=Feeds%3A%20RSS%2FAtom&utm_source=Life&utm_content=2274635

- QUEBEC | *Montreal Gazette* (Letter) – 12 December 2011 – **'What the end-of-life report actually said.'** Margaret Somerville concludes her recent critique of the Royal Society of Canada's Expert Panel Report on End of Life Decision Making¹ ... by saying that "there is a wealth of grounds on which this report can be easily dismissed." She does not provide readers with any of those grounds. Her reading of the arguments contained in the report calls for a response. To begin with, Prof. Somerville makes no mention of the fact that many of our principal recommendations have to do with increasing the level and the quality of palliative care available to terminally ill patients in Canada. Her article gives the impression that our report is limited to the defence of physician-assisted suicide and euthanasia; she calls it a "pro-euthanasia manifesto." That is a misleading portrayal, to say the least. Second, she states that "many of the report's authors are well-known euthanasia advocates, as are the people whom the panel consulted," as if this were sufficient grounds to dismiss the report. Some of the authors of the report have taken public stands in favour of decriminalization of euthanasia, while others ... have never voiced any opinions on the topic. But of what relevance is this to a consideration of the arguments in the report? Should the fact that Prof. Somerville is herself a well-known euthanasia opponent suffice to make us dismiss her arguments? <http://www.montrealgazette.com/news/What+life+report+actually+said/5848364/story.html>

Specialist Publications

Of particular interest:

'Autonomy-based arguments against physician-assisted suicide and euthanasia: A critique' (p.13), published in *Medicine, Health Care & Philosophy*.

1. **'Assisted-suicide panel failed to present balanced arguments,'** *Montreal Gazette*, 7 December 2011 (noted in Media Watch dated 12 December 2011). Responding to the Royal Society of Canada's Expert Panel Report on End-of-Life Decision Making,¹ which recommended the legalization of euthanasia and physician-assisted suicide, a *Gazette* editorial called for "a national debate on life-and-death issues."² It is not "a careful, balanced review of various pros and cons of decriminalization of physician-assisted death from well-reasoned ethical and legal standpoints" required in the panel's mandate. <http://www.montrealgazette.com/health/Assisted+suicide+panel+failed+present+balanced+arguments/5826773/story.html>
 1. *Royal Society of Canada Expert Panel: End of Life Decision Making*, November 2011 (noted in Media Watch dated 21 November 2011). http://www.rscsrc.ca/documents/RSCEndofLifeReport2011_EN_Formatted_FINAL.pdf
 2. 'We need a national debate on life-and-death issues,' *Montreal Gazette* (OpEd), 24 November 2011 (noted in Media Watch dated 28 November 2011). <http://www.montrealgazette.com/news/need+national+debate+life+death+issues/5758661/story.html>

U.S.A.

Expressions of loss and separation

For the fallen, an esoteric, simple symbol of grief

NEW YORK TIMES | Online article – 16 December 2011 – The locker that nobody wants to open is on the seventh floor of a massive police building on East 20th Street. Turn left out of the elevator, then walk down a hall and through a cluttered computer training classroom, to a door in the rear marked Ceremonial Unit. Another left into a little dead-end hall, and there it is, the last locker on the left, marked No. 2064. It's as if someone wanted to make it hard to find. This is where the New York Police Department keeps its pleated mourning fans. There is a lock on the metal door, but somebody who knows the combination is usually within shouting distance. The response time in the little hallway is as urgent to this unit as any anti-terrorist exercise on the streets outside. http://www.nytimes.com/2011/12/17/nyregion/simple-symbols-of-mourning-for-new-yorks-fallen.html?_r=1

Advance directives

Having to think about the unthinkable

CALIFORNIA | *Los Angeles Times* – 14 December 2011 – Most people don't like to plan for dying, but in our state of denial, we leave ourselves vulnerable to conditions we would never want. Arrangements for the end of life are essential. "I could show you case after case," said Dr. Neil S. Wenger. "I could bet you million-to-1 odds these patients would not want to be in this situation." He was talking about patients in critical condition who are "attached to machines, being kept alive" in hospitals, many of them suffering. A common reason for that, said Wenger, of the Health System Ethics Center [University of California, Los Angeles], is that fewer than one-third of us make our healthcare wishes known in advance of critical illness or injury. So if we end up comatose after an accident, or with severe memory loss in old age, we're kept alive, regardless of the cost and regardless of what our wishes might be or how grim the prognosis. It's understand-able. Nobody wants to think in advance about life ending. We want to believe medical advances will keep us healthy until we die in our sleep at a ripe old age. But death doesn't always come on our terms, and failing to face up to other possibilities can put crushing burdens on loved ones – not to mention that soaring end-of-life medical costs are at the center of the national budget crisis. <http://www.latimes.com/news/local/la-me-lopez-howyoudie-20111212.0.5568339.column>

Escaping ICU hell

NATIONAL JOURNAL | Online article – 15 December 2011 – Late-life care is arguably the most flawed precinct of a troubled medical system. It is also a sector that growing numbers of Americans will encounter, as more of us live longer. Longevity, of course, is good. But for how many of us will it mean additional years of sickness, frailty, decline? For how many will it mean more medical care than we need or want? http://www.nationaljournal.com/njonline/no_20100508_1960.php/escaping-icu-hell-20111215

Of related interest:

- REUTERS | Online report – 15 December 2011 – **'Many surgeons don't discuss post-op medical wishes.'** A new survey of surgeons¹ suggests many fail to discuss their patients' wishes in case a risky operation goes awry, and even more would not operate if patients limited what could be done to keep them alive. <http://www.reuters.com/article/2011/12/15/us-surgeons-medical-wishes-idUSTRE7BE2AR20111215>

1. 'Use of advance directives for high-risk operations,' *Annals of Surgery*, published online 1 December 2011. <http://journals.lww.com/annalsofsurgery/pages/articleviewer.aspx?year=9000&issue=00000&article=98960&type=abstract>

Cont.

- *FORBES* | Online article – 14 December 2011 – **'Create your own "death panel."** We experience people around us getting sick and/or dying, and know it will happen to us one day, just not any time soon. So we nervously laugh and say, "Don't let that happen to me" and never write it down. When sickness suddenly happens and you have tubes hanging from almost every orifice, unable to declare your wishes, your family will say, "I don't think Mom would want that." But no one can really remember details. <http://www.forbes.com/sites/carolynmcclanahan/2011/12/14/create-your-own-death-panel/>

From Media Watch dated 31 October 2011:

- *WALL STREET JOURNAL* | Online article – 24 October 2011 – **'Informed patient: Advance directives cut unwanted hospitalizations.'** Frail elderly patients who have advance directives through a program to communicate treatment preferences have fewer unwanted hospitalizations, according to a new study.¹ <http://blogs.wsj.com/health/2011/10/24/informed-patient-advance-directives-cut-unwanted-hospitalizations/>

1. 'The consistency between treatments provided to nursing facility residents and orders on the Physician Orders for Life-Sustaining Treatment form,' *Journal of the American Geriatric Society*, published online 22 October 2011. <http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2011.03656.x/abstract>

Interpreting health directives

Hospital merger foes, backers share views

KENTUCKY | *Courier-Journal* (Louisville) – 14 December 2011 – Appearing for the first time publicly on the same panel, proponents and critics of a planned hospital merger ... shared their views and answered questions about money, reproductive services and end-of-life care in a sometimes heated exchange. The merger ... would combine University Hospital with Jewish Hospital & St. Mary's HealthCare and Lexington-based St. Joseph Health System. St. Joseph is owned by Catholic Health Initiatives [CHI] of Denver. CHI follows Catholic health directives, and the other merger partners have agreed not to perform certain services forbidden by those directives. <http://www.courier-journal.com/article/20111214/NEWS01/312140096/Hospital-merger-foes-backers-share-views?odyssey=tab%7Ctopnews%7Ctext%7CHome>

From Media Watch dated 21 March 2011:

- *THE HASTINGS REPORT*, 2011;41(2):28-29. **'Making sense of the Roman Catholic directive to extend life indefinitely.'** The U.S. Conference of Catholic Bishops issued *Ethical & Religious Directives for Catholic Health Care Services*,¹ requiring all patients (including those in the so-called persistent vegetative state) be provided with artificial hydration and nutrition if such care could extend life indefinitely. <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5164>

1. *Ethical & Religious Directives for Catholic Health Care Services* (Fifth Edition), U.S. Conference of Catholic Bishops, November 2009. <http://www.ncbcenter.org/document.doc?id=147>

Of related interest:

- Scroll down to [Specialist Publications](#) and **'Hydration and nutrition at the end of life: A systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff'** (p.12), published in *Psycho-Oncology*.

No veteran dies alone

CBS NEWS | Online report – 12 December 2011 – Some 1,800 veterans die at Veterans Affairs facilities each day. "A dignified death is one of the most precious gifts anyone can give," says Dr. Wessel Meyer, chief of the medical staff. He oversees the end-of-life program aptly named "No veteran dies alone." http://www.cbsnews.com/8301-18563_162-57341845/a-va-promise-no-veteran-dies-alone/

When care is worth it, even if end is death

NEW YORK TIMES | Online OpEd – 12 December 2011 – You've probably heard that we spend a lot of money on patients who die. It's true: about one-tenth of the money spent on direct care goes to people who die each year. Among Medicare patients, the figure is much higher, about one-quarter. You may be shocked by those statistics. What health care system would squander so many dollars on patients who don't benefit? Or maybe you're saddened. No humane system would subject patients to painful interventions and procedures that serve no purpose. The idea that we waste money on terminal patients has caught on; the simplicity of the conceit makes it appealing to policy makers. And the data to support it keep coming, because it is easy for researchers to measure how much is spent on patients before they die. For instance, researchers at Dartmouth College publish rankings of hospitals and states based not on how successful they are at preventing deaths of patients who are very

ill, but on how much they spend on those they fail to save.¹ The same is true of some of the latest doctor quality measures promoted by national organizations, including some for cancer doctors. These examine how often these doctors' patients were given medications that could prolong their lives or alleviate their suffering before they died. In the metric-maker's eyes, treating such patients before they die is bad, not good. <http://www.nytimes.com/2011/12/13/health/policy/when-care-is-worth-it-even-if-end-is-death.html>

Specialist Publications

Of particular interest:

'Health care costs in end-of-life and palliative care: The quest for ethical reform' (p.11), published in the *Journal of Social Work in End-Of-Life & Palliative Care*.

1. *Trends & Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness*, Dartmouth Institute for Health Policy & Clinical Practice, April 2011 (noted in Media Watch dated 18 April 2011). http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf

Media Watch Online

The weekly report can be accessed at several websites, among them:

Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx>

Ontario | HPC Consultation Services: <http://www.hpconnection.ca/newsletter/inthenews.html>

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

U.S.A.

Prison Terminal: <http://www.prisonterminal.com/news%20media%20watch.html>

International

Global | Palliative Care Network Community: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

International Palliative Care Resource Center: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/news.htm>

International

Shocking neglect of patients with dementia must end

U.K. (ENGLAND & WALES) | *Daily Express* (OpEd) – 16 December 2011 – A report this week, the National Audit Of Dementia Care In General Hospitals carried out by the Royal College of Psychiatrists, paints a distressing picture of the treatment of elderly patients.¹ Just a few paces from the operating theatres packed with 21st-century technology some of the most vulnerable members of society are being neglected or even treated with contempt. Elderly people who lack the ability to feed themselves are having hot food plonked in front of them and left to go cold. Patients are being left to wet themselves because staff fail to answer their calls for help, or becoming dehydrated because they are not offered drinks. Too often, hospitals treat dementia sufferers as an inconvenience – “bed-blockers” as they have been contemptuously termed. To some extent I can sympathise with the hospitals. One quarter of acute hospital beds at any

one time are occupied by dementia patients, many of whom ought to be in residential care homes leaving the beds available for people about to undergo, or recovering from, surgery. <http://www.express.co.uk/posts/view/290401>

Extract from Royal College of Psychiatrists report:

The National Institute for Health & Clinical Excellence dementia guideline stresses the importance of the palliative care approach in dementia care and specifies the responsibility of health and social care practitioners and commissioners to ensure that people with dementia have equivalent access to palliative care. 35% (36/104) of hospitals said that the dementia care pathway interfaced with the end of life or palliative care pathway.

1. 'Report of the National Audit of Dementia Care in General Hospitals 2011,' Royal College of Psychiatrists, December 2011. <http://www.rcpsych.ac.uk/pdf/NATIONAL%20REPORT%20-%20Full%20Report%200512.pdf>

Economics of elder care

Families betrayed over care homes funding: Reforms that would let elderly keep their homes are shelved for a decade

U.K. | *Daily Mail* – 14 December 2011 – The scandal of pensioners selling their homes to pay for residential care could drag on until 2025. It had been hoped a fairer system would be in place by 2015 but it emerged last night that it might take a decade longer. In a further blow, Health Secretary Andrew Lansley refused to rule out a pensioner tax to pay for old age care. Ministers also admit that people will have to take more responsibility for themselves by spending thousands on insurance schemes or by releasing equity in their homes. Campaigners expressed outrage at the likely delay, which would see hundreds of thousands more pensioners having to sell up – denying their children an inheritance. <http://www.dailymail.co.uk/news/article-2073813/Care-home-reforms-let-elderly-house-shelved-decade.html?ito=feeds-newsxml>

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>

Expressions of loss and separation

Learning not to 'shun' other people's grief

IRELAND | *Irish Times* (Dublin) – 13 December 2011 – We are not good at handling other people's grief. We avoid the subject or, worse, the person who is bereaved, or we say stupid things such as, "Sure he had a good innings," which is just an invitation to dismiss the dead person. Men, for all our famed reluctance to discuss our feelings, are probably not much worse than women when it comes to handling the losses suffered by our friends. Both genders are liable to shun the bereaved person or to say things that are unhelpful. "Shun" may seem like an unfairly strong word, but if enough people avoid talking to a bereaved person because they don't know what to say, the effect can be that they feel shunned. I think that we want people to get over their grief because their grief upsets us. It reminds us of our own approaching death; it reminds us also that our whole world can be ruptured by the absence of another person; and the closest we can get to a return to normality is for the bereaved person to get over their loss and back to normality – our normality, that is, because for the grieving person the old normality is no longer possible.
<http://www.irishtimes.com/newspaper/health/2011/12/13/1224308996677.html>

U.K. National End of Life Care Intelligence Network updated End of Life Care Profiles

U.K. (ENGLAND) | National End of Life Care Intelligence Network – 13 Decembers 2011 – The End of Life Care Profiles present data on place of death and cause of death, by age and sex, for each Local Authority in England using the InstantAtlas mapping tool. The data can be viewed in map, chart and table format. The tool has been designed to make it easy to compare statistics across Local Authority areas. The Profiles are used by policy makers, commissioners and providers of end of life care services, among others, to identify areas and populations of need.
<http://www.endoflifecare-intelligence.org.uk/profiles.aspx>

Economics of life-threatening illnesses

Cancer costs 'set to rise by 62%'

U.K. | Press Association – 12 December 2011 – The cost of diagnosing and treating cancer patients may rise by nearly two thirds over the next decade, a report has found. Healthcare analysts Laing & Buisson warned that cancer survival rates in the U.K. could fall behind other developed nations because diagnosis and treatment costs are likely to increase by 62%, from £9.4 billion in 2010 to £15.3 billion by 2021. It will mean that the average cost of treating someone diagnosed with cancer will go from £30,000 in 2010 to almost £40,000 in 2021. 'The Cancer Diagnosis & Treatment: A 2021 Projection' report¹ ... says: "If we do not address the rising cost of cancer, we are unlikely to be able to afford the desired and expected level of cancer diagnosis and treatment over the next 10 years and beyond." This possibility will mean that the U.K.'s cancer survival rate could fall even further behind that of other developed countries." Data from the Organisation for Economic Co-operation & Development revealed ... that the U.K. is lagging behind other countries on average survival rates for breast, bowel and cervical cancer. The predicted leap in costs would come largely as a result of Britain's ageing population, which is predicted to lead to a 20% growth in cancer rates by 2021. An increase in the cost of technology and treatments used to combat the disease will also be a contributing factor.
<http://www.google.com/hostednews/ukpress/article/ALeqM5iVQpDXm86Q-rXgpiRcZxnlqmy6eg?docId=N0390091323608767112A>

1. 'The Cancer Diagnosis & Treatment: A 2021 Projection,' Laing & Buisson (Healthcare Analysts), December 2011. http://www.bupa.com/media/355766/cancer_diagnosis_and_treatment_-_a_2021_projection_-_final.pdf

End-of-life decisions

Bid to boost number of organ donors

U.K. (ENGLAND & WALES) | Press Association – 12 December 2011 – New guidance designed to boost the number of organs for transplant has been issued to the National Health Service.¹ It contains advice on how staff should approach families as their loved ones near the end of their lives, including using "positive" phrases to describe donation and avoiding "apologetic or negative language." http://www.google.com/hostednews/ukpress/article/ALeqM5gzx6JA3v5BuTDCRo4tkC39uQa1_A?docId=N0384721323572042342A

1. 'Organ donation for transplantation: Improving donor identification and consent rates for deceased organ donation,' Centre for Clinical Practice, National Institute for Health & Clinical Excellence, December 2011. <http://www.nice.org.uk/nicemedia/live/13628/57508/57508.pdf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Guardian* – 15 December 2011 – '**General Medical Council to draw up new advice.**' Medical regulators are considering how to deal with allegations that doctors have helped people kill themselves after a patient asked them what support, if any, doctors could give to people considering ending their own lives. The General Medical Council (GMC) says doctors are already bound by the law that assisting or encouraging suicide remains a criminal offence but believes it needs to clarify how its own investigators deal with cases where no prosecution is mounted but complaints are still made about a doctor's fitness to practise. More than 150 Britons have travelled to ... Switzerland, to end their own lives. <http://www.guardian.co.uk/society/2011/dec/15/assisted-suicide-new-advice?newsfeed=true>

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

Effectively training the hospice and palliative medicine physician workforce for improved end-of-life health care in the U.S.

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE | Online article – 15 December 2011 – The widening gap between the demand for palliative care services and the supply of trained palliative care professionals has resulted in considerable end-of-life distress for patients. Without formal training in palliative medicine and end-of-life symptom management, physicians in the U.S. are less equipped to competently address seriously ill and dying patients' medical, emotional, and spiritual needs. Recent attempts within graduate medical education training deliberately seek to prepare a critical mass of physicians as the new hospice and palliative medicine workforce in the U.S. In addition, healthcare reform proposals may re-define the National Health Service Corps post-graduate training over the next five years and the Hospice Medicare Benefit altogether. Healthcare policy options include steady changes at multiple levels of medical training – namely, medical school curriculum mandates, requiring all graduate physician residency training to foster patient-centered communication skills and discussions about advanced directives, and instituting palliative medicine proficiency Continuing Medical Education requirements for all states' medical licensing boards. <http://ajh.sagepub.com/content/early/2011/12/04/1049909111429325.abstract>

Of related interest:

- *HAWAII MEDICAL JOURNAL*, 2011;70(11):239-41. '**Towards cultural competency in end-of-life communication training.**' To meet the needs of a more diverse population, a culturally sensitive approach to end-of-life communication is critical. This paper describes a unique communication workshop that introduces future physicians to the delivery of culturally responsive care for patients in palliative and end-of-life treatment. <http://www.ncbi.nlm.nih.gov/pubmed/22162603>

Continuity of care

Using network analysis to map the formal clinical reporting process in pediatric palliative care: A pilot study

BMC HEALTH SERVICES RESEARCH | Online article – 16 December 2011 – In this report the authors applied network analysis to paper records of clinical consultations and reports for 6 patients with complex conditions. A high degree of discontinuity was identified, and care was fragmented amongst specialist and generalist providers. Information was shared selectively and often moved in only one direction. Families have anecdotally reported frustration with poor continuity of care. Network analysis can be a useful tool in describing the discontinuity of care experienced by families dealing with complex and chronic conditions. This tool could be expanded to other systems such as electronic health records and many other health care situations. <http://www.biomedcentral.com/content/pdf/1472-6963-11-343.pdf>

Of related interest:

- *JOURNAL OF THE NATIONAL CANCER INSTITUTE* | Online article – 14 December 2011 – '**Pediatric palliative care in Europe expands.**' Despite a long European tradition of government-funded National Health Service, few freestanding pediatric palliative-hospice care facilities receive sufficient, if any, federal funding and must rely on charitable contributions from the corporate and private sectors. However, cost is only one hurdle. Pediatric palliative care training modules for medical specialists and nursing staff have traditionally been scarce. But a slate of new educational initiatives and models of care are emerging across Europe. Three models in particular have taken hold: in-hospital pediatric palliative services, freestanding facilities, and in-home community support services. <http://jnci.oxfordjournals.org/content/early/2011/12/14/jnci.djr537.extract>

Public opinion on preferences and priorities for end-of-life care in sub-Saharan Africa: Piloting a novel method of street surveying

BMJ SUPPORTIVE & PALLIATIVE CARE | Online article – 13 December 2011 – There is a great need for end-of-life care in Africa due to the high incidence of life-threatening illness. However, little is known about the views of the African public on end-of-life care. Therefore, the authors piloted a street survey in Nairobi (Kenya), where adult pedestrians were randomly interviewed about local preferences and priorities for end-of-life care. Interviewers' field notes revealed no major problems with content, but identified tribal and ethnic origin as a sensitive topic, and stressed the usefulness of the presence of a 'buddy' for the safety of the interviewer. Methodological and implementation lessons have been learnt and the results of the pilot suggest street surveying is a feasible and acceptable method to examine public opinion on end-of-life care in Africa, provided people are able to freely decline to respond and safety measures are in place for interviewer. <http://spcare.bmj.com/content/early/2011/12/13/bmjspcare-2011-000112.abstract>

Palliative care in emergency departments: An impossible challenge?

EUROPEAN JOURNAL OF EMERGENCY MEDICINE | Online article – 12 December 2011 – The aim of this study was to investigate the care practices surrounding end-of-life patients and the scope for providing palliative care in two emergency department short-stay units. Two qualitative methods of investigation were used: direct ethnographic-type observation and semi-directed group interviews. The results highlight the fact that end-of-life situations inflect the practices of care and give rise to adjustments in the organization of work. These practices operate in two registers: that of supporting the family and that of attention to the patient's comfort. The authors propose a typology of end-of-life patients. The practices termed 'palliative care' by the caregivers are addressed to terminally ill patients expected to die shortly. http://journals.lww.com/euro-emergencymed/Abstract/publishahead/Palliative_care_in_emergency_departments_an.99720.aspx

Cont.

From Media Watch dated 5 December 2011:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 2 December 2011 – **'Emergency medicine physicians' perspectives of providing palliative care in an emergency department.** Overall, respondents felt that palliative care is not prioritized appropriately, leading patients to be unaware of their options for end-of-life care. Providing educational materials and courses that have been developed from the ED [emergency department] perspective should be included in ongoing continuing medical education. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0106>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2011;42(5):657-662. **'A rapid two-stage screening protocol for palliative care in the emergency department: A quality improvement initiative.'** [http://jpsmjournals.com/article/S0885-3924\(11\)00403-9/abstract](http://jpsmjournals.com/article/S0885-3924(11)00403-9/abstract)

From Media Watch dated 21 November 2011:

- *CRITICAL CARE MEDICINE* | Online article – 10 November 2011 – **'Integrating palliative care in the surgical and trauma intensive care unit: A report from the Improving Palliative Care in the Intensive Care Unit Project Advisory Board and the Center to Advance Palliative Care.'** http://journals.lww.com/ccmjournals/Abstract/publishahead/Integrating_palliative_care_in_the_surgical_and.98189.aspx

Prognosis: Important information when obtaining informed consent

JOURNAL OF PALLIATIVE CARE & MEDICINE | Online article – Accessed 16 December 2011 – Informed consent must be obtained in advance of all personal care, investigations, and treatments. For informed consent to be complete and valid, the person giving consent must be capable of making decisions, act voluntarily, and be provided with all necessary information to arrive at a decision that will be in the best interests of the patient. Information sharing has generally focused on available options, risks and benefits of a given intervention, and implications of foregoing the intervention. However, it is difficult to interpret such information without a discussion about the clinical context, natural history of disease, and its associated prognosis. Prognostication, consisting of both the computation (formulation) and disclosure of prognosis, is a key facilitator and enabler for the delivery of truly patient-centered care. Studies have demonstrated that despite patients desiring prognostic information, significant gaps in communication occur between physicians and patients. In a majority of cases of patients with advanced illness there is evidence that disclosure of prognosis has not occurred, thus raising the question as to whether the "informed consent" in this setting is ethically and legally valid. <http://omicsgroup.org/journals/JPCM/JPCM-1-101.pdf>

Leveraging external resources to grow and sustain your palliative care program: A call to action

JOURNAL OF PALLIATIVE MEDICINE | Online article – 14 December 2011 – Just as palliative care programs benefit from marketing and education plans, they also benefit from a plan to leverage external resources. Largely a missed opportunity, external resources such as organizations, networks, and experts can help palliative care service (PCS) leaders and team members gain information on everything from best practices to funding opportunities, while serving as sources for personal and professional support. The growing number of active PCSs and the increasing availability of support and expertise ensure that new programs no longer have to face challenges alone. Further, the steady increase in the number of new programs has created opportunities for those who are more experienced to serve as mentors for peers who are navigating the challenges of growing and sustaining a clinical service. The authors encourage both mentors and mentees to seek support from or provide support to others in the field. Leveraging the collective expertise and experiences in our field can ensure that palliative care continues to thrive and grow. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2011.0280>

Survey of neonatologists' attitudes toward limiting life-sustaining treatments in the neonatal intensive care unit

JOURNAL OF PERINATOLOGY | Online article – 15 December 2011 – Across clinical scenarios and as general ethical concepts, withdrawal of mechanical ventilation in severely affected patients was most accepted by respondents; withdrawal of artificial nutrition and hydration was least accepted. One-third ... did not agree that non-initiation of treatment is ethically equivalent to withdrawal. Around 20% ... would not defer care if uncomfortable with a parent's request. Respondents resources included ethics committees, American Academy of Pediatrics guidelines and legal counsel/courts. <http://www.nature.com/jp/journal/vaop/ncurrent/full/jp2011186a.html>

From Media Watch dated 22 August 2011:

- U.S. (ILLINOIS) | *Chicago Tribune* – 18 August 2011 – '**Short lives, troubling questions.**' How much should be done, and at what cost, to prolong a life? Medical advances present doctors with that dilemma every day, whether they deal with critically ill infants or adults with end-stage cancer. http://www.chicagotribune.com/news/opinion/editorials/ct-edit-twins-20110818_0_2528437_story

From Media Watch dated 11 July 2011:

- *U.S. NEWS & WORLD REPORT* | Online report – 5 July 2011 – '**Medical futility trend seen in neonatal deaths.**' Most deaths that occur in neonatal intensive care units at U.S. hospitals are due to withdrawal of life support and the withholding of lifesaving measures, a new study reveals.¹ <http://health.usnews.com/health-news/managing-your-healthcare/articles/2011/07/05/medical-futility-trend-seen-in-neonatal-deaths>

1. 'How infants die in the neonatal intensive care unit,' *Archives of Pediatrics & Adolescent Medicine*, 2011; 165(7):630-634. <http://archpedi.ama-assn.org/cgi/content/abstract/165/7/630>

From Media Watch dated 23 May 2011:

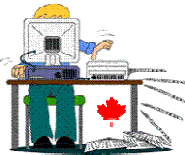
- *BMC PEDIATRICS* | Online article – 21 May 2011 – **Withdrawal of life-support in paediatric intensive care – a study of time intervals between discussion, decision and death.** The authors investigated the time required for end-of-life decisions, subsequent withdrawal of life-sustaining treatment and the time to death. Wide case-by-case variation in timeframes occurs at every step of the process of withdrawal of life-sustaining treatment until death. This knowledge may facilitate medical management, clinical leadership, guidance of parents and inform organ procurement after cardiac death. <http://www.biomedcentral.com/content/pdf/1471-2431-11-39.pdf>
- *BRITISH MEDICAL BULLETIN* | Online article – 19 May 2011 – '**Guidance for withdrawal and withholding of intensive care as part of neonatal end-of-life care.**' The child's 'best interests' take precedent and clinical guidance has been published to support the joint decision-making partnership of clinicians and families. Withholding and withdrawing intensive care should be part of an overall end-of-life care plan incorporating the principles and standards of palliative care. <http://bmb.oxfordjournals.org/content/early/2011/05/18/bmb.idr016.abstract>

Health care costs in end-of-life and palliative care: The quest for ethical reform

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online article – 13 December 2011 – The authors offer an ethical perspective on health care cost control in the context of end-of-life and palliative care, an area considered by many to be a principal candidate for cost containment. However, the policy and ethical challenges may be more difficult in end-of-life care than in other areas of medicine. The authors discuss barriers to developing high quality, cost effective, and beneficial end-of-life care, and barriers to maintaining a system of decision making that respects the wishes and values of dying patients, their families, and caregivers. They also consider improvements in present policy and practice – such as increased timely access and referral to hospice and palliative care; improved organizational incentives and cultural attitudes to reduce the use of ineffective treatments; and improved communication among health professionals, patients, and families in the end-of-life care planning and decision-making process. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2011.623458>

Hydration and nutrition at the end of life: A systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff

PSYCHO-ONCOLOGY | Online article – 8 December 2011 – Decrease in oral intake, weight loss, and muscular weakness in the last phases of a terminal illness, particularly in the context of the cachexia-anorexia syndrome, can be an important source of anxiety for the triad of patient, family, and health staff. The present literature review examines the emotional impact of reduced oral intake as well as perceptions and attitudes toward assisted nutrition and hydration for terminally ill patients at the end of life, among patients, family, and health care staff. The authors have identified the ways in which emotional and cultural factors influence decision-making about assisted nutrition and hydration. Lack of information and misperceptions of medically assisted nutrition and hydration can play a predominant role in the decision to begin or suspend nutritional or hydration support. <http://onlinelibrary.wiley.com/doi/10.1002/pon.2099/full>



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>

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 tool or change document.

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Something Missed or Overlooked?

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

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *AUSTRALIAN & NEW ZEALAND JOURNAL OF PSYCHIATRY*, 2011;45(12):1017-1019. **'What's it got to do with you?' Challenging the medical profession's future in the assisted suicide debate.** No abstract. <http://informahealthcare.com/doi/full/10.3109/00048674.2011.623661>
- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online article – 8 December 2011 – **'Autonomy-based arguments against physician-assisted suicide and euthanasia: A critique.'** Respect for autonomy is typically considered a key reason for allowing physician assisted suicide and euthanasia. However, several recent papers have claimed this to be grounded in a misconception of the normative relevance of autonomy. It has been argued that autonomy is properly conceived of as a value, and that this makes assisted suicide as well as euthanasia wrong, since they destroy the autonomy of the patient. According to one interpretation, autonomy is a personal prudential value, which may provide a reason why euthanasia and assisted suicide might be against a patient's best interests. According to a second interpretation, inspired by Kantian ethics, being autonomous is unconditionally valuable, which may imply a duty to preserve autonomy. The authors argue that both lines of reasoning have limitations when it comes to situations relevant for end-of life care. <http://www.springerlink.com/content/154g594783nw7026/>

Worth Repeating

U.S. Institute of Medicine: 1997 Expert Panel

Not enough is done to ease end of life, panel says

U.S. | *New York Times* – 5 June 1997 – Too many Americans are denied a chance to die well because of inadequate care and lack of understanding of their needs, an expert panel from the Institute of Medicine said today. The 12-member panel said many Americans suffered preventable pain and stress at the end of life. The experience is so poorly managed by doctors and other health workers, as well as insurers, that many people see death as a degrading, painful episode that leads to talk of assisted suicide, the panelists said. "Americans have come to fear that they will die alone, and that they will die in distress or pain," Dr. Christine Cassel, chairwoman of the panel, said at a news conference. "This does not have to be the case." There are signs that the health care system is finally taking the issues of dying seriously, but too many are still dying without the benefit of skillful and compassionate care, said Dr. Cassel, chairwoman of

geriatrics and adult development at Mount Sinai Medical Center in New York City. American medicine emphasizes high-tech cures, surgery and aggressive treatment to save patients, the committee said in a report, and not what happens when death becomes inevitable. Many doctors are ill-prepared to deal with death or to help patients and their families face the end of life. <http://www.nytimes.com/1997/06/05/us/not-enough-is-done-to-ease-end-of-life-panel-says.html>

Extract from *New York Times* article

Studies show that a majority of dying patients experience severe, undertreated pain and many feel that modern treatment often helps prolong agony while failing to prepare patients adequately for death, committee members said.

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