## 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.

## 29 April 2013 Edition | Issue #303



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

Compiled & Annotated by Barry R. Ashpole

Critical conversations: Scroll down to <u>Specialist Publications</u> and 'One last teaching moment' (p.13), in *Journal of the American Medical Association*.

## **Canada**

## Keeping elderly out of care homes focus of Saskatchewan government

SASKATCHEWAN | CJME News (Regina) -24 April 2013 - Health Minister Dustin Duncan insists setting staffing standards is not something the government is currently considering. He says each health region gets a quarterly report on staffing from each care home and he doesn't see reason for alarm. He says mandated staffing or additional beds aren't necessarily the answer to improving long-term care. He insists Saskatchewan already has more beds per capita than other provinces for people over 70. He says the way to improve long term care for seniors is by keeping them out of those facilities in the first place. That's why the government is increasing spending on providing assistance to seniors in their own homes. He says the way to improve long term care for seniors is by keeping them out of those facilities in the first place. That's why the government is increasing spending on providing assistance to seniors in their own homes. http://cjme.com/story/keepingelderly-out-care-homes-focus-saskgovernment/106879

## **Specialist Publications**

'Improving end-of-life care in nursing homes: Implementation and evaluation of an intervention to sustain quality of care' (p.16), in *Palliative Medicine*.

## **Corrections & Clarifications**

Noted in Media Watch (1 April 2013) was 'Province introduces plan to improve end-of-life care' (p.2), broadcast on 1130 Radio News, Vancouver. 'The Provincial End-of-Life Care Action Plan for British Columbia' can be downloaded at: <a href="http://www.health.gov.bc.ca/library/publications/year/2013/end-of-life-care-action-plan.pdf">http://www.health.gov.bc.ca/library/publications/year/2013/end-of-life-care-action-plan.pdf</a>



12 October 2013

http://www.worldday.org/

## [Ontario Premier] Wynne promises \$185M to improve home care for seniors

ONTARIO | CTV News (Toronto) – 23 April 2013 – Ontario's governing Liberals will spend \$185 million more this year to reduce wait times for seniors who need home care, Premier Kathleen Wynne said. They're setting a target for seniors who require "complex" treatment to receive home care within five days of being assessed. They're also spending another \$75 million this year on community care. It will help about 46,000 patients get the care they need. But it also appears to be a survival tactic aimed at appeasing the New Democrats, who are demanding quicker home care in the May

budget as a condition of their support. http://toronto.ctvnews.ca/wynne-promises-185m-to-improve-home-care-for-seniors-1.1250567

#### **Specialist Publications**

'Supporting home care for the dying: An evaluation of healthcare professionals' perspectives of an individually tailored hospice at home service' (p.13), in *Journal of Clinical Nursing*.

Noted in Media Watch, 8 April 2013:

ONTARIO | CTV News – 4 April 2013 – 'Provinces need to follow through on home care funding commitments: Report.' Canada's provinces and territories talk a good game when it comes to funding in-home health care, but a new report is urging all orders of government to put their money where their mouths are. <a href="http://www.ctvnews.ca/canada/provinces-need-to-follow-through-on-home-care-funding-commitments-report-1.1223641">http://www.ctvnews.ca/canada/provinces-need-to-follow-through-on-home-care-funding-commitments-report-1.1223641</a>

## Parents should have choice to remove feeding tubes from terminally ill children: Study

ONTARIO | The National Post - 23 April 2013 - Months after the fact, one mother admits she and her husband have still told no one about their heart-wrenching decision to have food and fluid tubes removed from their dying child. "I thought a lot of people would think it was disgusting and horrible and murderous if we ever said that we were going to take away the food," the woman told researchers behind a new Canadian study.1 "I just thought that people would think it was, you know, paramount to murder." Yet she and almost a dozen other parents surveyed by a team at Toronto's Sick Kids hospital said ending artificial nutrition actually made their children more comfortable and peaceful in their final days. The study's authors conclude that removing feeding and hydration tubes from young, terminal patients is a process medical staff should make available - and without exposing parents to health workers' personal objections to the practice. The benefits in some

rare cases are well known to the few specialists who work with child palliative patients, said Dr. Adam Rapoport, the study's lead author. Many other health professionals, however, likely do not even consider the possibility, he said. "The default in pediatric medicine is that if we have technology to feed a child, we must use it." <a href="http://news.nationalpost.com/2013/04/23/parents-should-have-choice-to-remove-feeding-tubes-from-terminally-ill-children-study/">http://news.nationalpost.com/2013/04/23/parents-should-have-choice-to-remove-feeding-tubes-from-terminally-ill-children-study/</a>

## **Specialist Publications**

'Guidance on withholding and withdrawing treatment of sick children to be updated' (p.10), in *British Medical Journal*.

'A consensus for change: Parent and professional perspectives on care for children at the end of life' (p.11), in Issues in Comprehensive Pediatric Nursing.

'Parental perceptions of forgoing artificial nutrition and hydration during end-of-life care,' Pediatrics, 8 April 2013. Forgoing artificial nutrition and hydration in children at the end of life is an acceptable form of palliation for some parents and may contribute to a death that is perceived to be peaceful and comfortable. [Noted in Media Watch, 15 April 2013] <a href="http://pediatrics.aappublications.org/content/early/2013/04/03/peds.2012-1916.abstract">http://pediatrics.aappublications.org/content/early/2013/04/03/peds.2012-1916.abstract</a>

## Call for better palliative care

ONTARIO | *Timmins Daily Press* – 23 April 2013 – As Canada's population ages, the lack of palliative care services becomes increasingly problematic. MP Charlie Angus ... says the recent shut down of Perram House – a palliative care hospice in downtown Toronto<sup>1</sup> – is a wake-up call for the need for better services for families dealing with the death of a loved one. Angus is calling on all parliamentarians to help implement a national palliative care strategy. "Less than a quarter of Canadians have access to palliative care," he said. "In rural areas, the North and on First Nations [*sic*], the lack of services are highly problematic. This is one issue where we can work across party lines to ensure that all Canadians have access to proper access to end of life care." Angus pointed to a recent all-party study that came forward with numerous recommendations for a national palliative care strategy. http://www.timminspress.com/2013/04/22/angus-calls-for-better-palliative-care

- 'Perram House hospice closing... staff got two days' notice,' *The Toronto Star*, 10 April 2013.
   Perram House one of the few hospices in the city providing end-of-life care to marginalized, homeless and drug-addicted people will close. [Noted in Media Watch, 15 April 2013] <a href="http://www.thestar.com/life/health-wellness/2013/04/10/perram-house-hospice-closing-wednesday-staff">http://www.thestar.com/life/health-wellness/2013/04/10/perram-house-hospice-closing-wednesday-staff</a> got two days notice.html
- Not to be Forgotten: Care of Vulnerable Canadians, Ad Hoc (All Party) Parliamentary Committee on Palliative & Compassionate Care, 17 November 2011. While progress has been made, Canada still falls far short of quality end-of-life care for all, with only 16-30% of those who need it receiving palliative care. [Noted in Media Watch, 21 November 2011] <a href="http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf">http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf</a>

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online 25 April 2013 'Assisted suicide debate reignites; minister stands firm.' Canada's Justice Minister Rob Nicholson said even though the issue is "emotional and divisive" for many Canadians, he has "no intention of reopening this debate." He said in a written statement, "The laws surrounding euthanasia and assisted suicide exist to protect all Canadians, including those who are most vulnerable, such as people who are sick or elderly or people with disabilities." <a href="http://www.cbc.ca/news/health/story/2013/04/25/mb-assisted-suicide-debate-reopened-winnipeg.html">http://www.cbc.ca/news/health/story/2013/04/25/mb-assisted-suicide-debate-reopened-winnipeg.html</a>
- MANITOBA | CBC (Winnipeg) 25 April 2013 'Winnipeg's Susan Griffiths dies by assisted suicide in Zurich.' Susan Griffiths ... who went to Switzerland to take advantage of the country's assisted-suicide law, has died. Griffiths, 72, had multiple system atrophy, a rare disease that was robbing her of the ability to perform the most basic bodily functions. <a href="http://www.cbc.ca/news/canada/manitoba/story/2013/04/24/mb-susan-griffiths-assisted-suicide-final-blog.html?cmp=rss">http://www.cbc.ca/news/canada/manitoba/story/2013/04/24/mb-susan-griffiths-assisted-suicide-final-blog.html?cmp=rss</a>
  - **N.B.** Scroll down to International and 'Swiss groups fear study undercuts assisted suicide' (p.8).
- MANITOBA | CBC (Winnipeg) 22 April 2013 'Assisted suicide would jeopardize people with disabilities.' In theory, legal assisted suicide sounds compassionate and safe, promising autonomy. How could one person's decision about their own body possibly harm someone else? In reality, assisted suicide doesn't live up to its billing. For example, we know suicides can trigger copycat suicides, and we do everything possible to prevent such tragedies. But I hear nothing about discouraging copycat assisted suicides. Why the double standard? A clue to the double standard lies in the commonly used phrase "quality of life" (QoL). In medical contexts, QoL seems to be code for disability, pain and proximity to death with frequent conflation of these three. People with disabilities regularly encounter misperceptions of their "suffering" and pain. They find that others rate their lives and QoL lower than they do themselves. <a href="http://www.cbc.ca/news/canada/manitoba/story/2013/04/22/mb-assisted-suicide-against-essay-winnipeg.html">http://www.cbc.ca/news/canada/manitoba/story/2013/04/22/mb-assisted-suicide-against-essay-winnipeg.html</a>

■ MANITOBA | CBC (Winnipeg) – 22 April 2013 – 'Physician-assisted suicide: The case for legalization.' In Canada, if you are a competent adult, then you have the legal as well as the moral right to insist that life-support be withheld or withdrawn, even if this will result in your immediate death. If, however, you are suffering irremediably but are not dependent on technology to keep you alive then you may be stuck. Instructions to "pull the plug" provide a merciful exit from unbearable suffering only if you happen to be "lucky" enough to require life-support. There are other permissible escape routes from a prolonged and painful process of dying. You can, for example, legally choose to refuse all food and fluids, thereby starving yourself to death. Or you can choose "terminal sedation" – the administration of drugs that will make you unconscious until you die. Typically, when this happens, tube feeding and hydration will be also be withdrawn. <a href="http://www.cbc.ca/news/canada/manitoba/story/2013/04/22/mb-essay-in-favour-assisted-suicide-winnipeg.html">http://www.cbc.ca/news/canada/manitoba/story/2013/04/22/mb-essay-in-favour-assisted-suicide-winnipeg.html</a>

## U.S.A.

## Physicians debate whether patients need to know they're dying

CALIFORNIA | The Los Angeles Times – 25 April 2013 – In the days when American physicians dispensed oracular commands and their judgments were rarely guestioned, a doctor could take it upon himself with few ethical qualms to keep from a patient the bad news of a terminal diagnosis. For better or worse, those days may be well behind us. But physicians have not ceased debating one of the stickiest and most universal ethical quandaries of medical practice: How, when and why does one inform a patient that he or she is dying? The latest evidence of that ongoing discussion was published in the *British Medical Journal*.<sup>1,2</sup> The latest question in the journal's 'Head to Head' feature, "Do patients need to know they are terminally ill?," essentially pits one side's reasonable arguments that "we're all dying" and "you never really know when and of what a patient will die" against another side's equally compelling assertions that "knowledge allows better decisions" and "a patient can still have hope - to live to see a daughter married or achieve a cherished goal or to die a peaceful death at home." Either way, the two sides ... appear to converge on one key rule: Patients whose lives will probably be limited or ended by a disease deserve a forthright explanation of what treatment is available and what it probably would, and would not, accomplish if undertaken. Given that this is a matter of consensus, the difference seems to come down to how forcefully a doctor should press the point when a patient seems unwilling to face the realities of his or her diagnosis. http://www.latimes.com/health/boostershots/laheb-physicians-terminal-patients-20130424.0.1331439.story

- 'Do patients need to know they are terminally ill? No.' Patients do not need to be told that they
  are terminally ill. However, this does not mean we should pretend we can cure them of incurable illnesses or that we should withhold prognostic information from those who want it.
  http://www.bmj.com/content/346/bmj.f2560
- 2. 'Do patients need to know they are terminally ill? Yes.' Patients have the right to make informed decisions about their healthcare. Informed consent, and the process of balancing risks and benefits of treatment, is a fundamental ethical principle. This principle is no less relevant for a patient with terminal illness... <a href="http://www.bmj.com/content/346/bmj.f2589">http://www.bmj.com/content/346/bmj.f2589</a>
  - N.B. See related editorial, 'Helping patients to die well.' http://www.bmj.com/content/346/bmj.f2656

## 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. <a href="http://www.pcn-e.com/community/pg/file/owner/MediaWatch">http://www.pcn-e.com/community/pg/file/owner/MediaWatch</a>

## Video may help terminal patients make CPR choice

REUTERS | Online - 25 April 2013 - Terminally ill cancer patients who watched either of two videos about the option to forego resuscitation overwhelmingly elected that route for the patient in the video, if not for themselves, according to a new study. 1 But the vignettes - whose only difference was whether fictional patients decided on their own to skip cardiopulmonary resuscitation (CPR) or got a recommendation from their doctor - elicited high marks from real patients for the video doctors' compassion in discussing a difficult subject. Importantly, study participants didn't think less of a doctor who recommended that patients forgo life-saving efforts during cardiac arrest. "The reassuring finding here is that both approaches (doctor- versus patient-guided decisions about whether to be resuscitated) are likely to reach very similar results," said

study author Dr. Eduardo Bruera, department chair of palliative care and rehabilitation medicine in the cancer medicine division at the University of Texas MD Anderson Cancer Center in Houston. Dying cancer patients can survive cardiac arrest if given CPR, but experts note that most of those patients will suffer from serious complications and typically die within days to weeks. http://www.reuters.com/article/2013/04/25/us-video-cpr-idUSBRE93O16520130425

#### **Specialist Publications**

'National assessment of living wills and do not resuscitate orders' (p.9), in *BMJ Supportive* & *Palliative Care.* 

'Patient-physician communication about code status preferences,' Cancer, 5 April 2013. Ending DNR discussions with a question or a recommendation did not impact DNR choice or perception of physician compassion. Therefore, both approaches are clinically appropriate. <a href="http://onlinelibrary.wiley.com/doi/10.1002/cncr.27981/abstract">http://onlinelibrary.wiley.com/doi/10.1002/cncr.27981/abstract</a>

## Bill aims to give Maine seniors another option to pay for end-of-life care

MAINE PUBLIC BROADCASTING NETWORK | Online – 24 April 2013 – According to the National Institutes of Health, nearly 7 in 10 people over age 65 will need long term care at some point in their lives. A recent poll finds most Americans don't believe they'll ever need long-term care, and don't plan for it. The bill seeks to help seniors pay for care using life insurance policies. <a href="http://www.mpbn.net/News/MaineNewsArchive/tabid/181/ctl/ViewItem/mid/3475/ItemId/27619/Default.aspx">http://www.mpbn.net/News/MaineNewsArchive/tabid/181/ctl/ViewItem/mid/3475/ItemId/27619/Default.aspx</a>

 'Long Term Care Study,' Associated Press-NORC Center for Public Affairs Research (at the University of Chicago), April 2013. <a href="http://www.apnorc.org/PDFs/Long%20Term%20Care/AP-NORC%20LTC%20Final%20Topline.pdf">http://www.apnorc.org/PDFs/Long%20Term%20Care/AP-NORC%20LTC%20Final%20Topline.pdf</a>

## Race and geography may influence late-stage kidney care

REUTERS | Online – 24 April 2013 – At the end of life, black kidney disease patients are more likely than white patients to continue intensive dialysis instead of choosing hospice care, according to a new study. Researchers also found that racial differences in kidney disease treatments became more extreme in the highest Medicare spending regions of the U.S. Racial differences exist; when you add the component of geography, those racial differences widen, said study author Dr. Bernadette Thomas, senior clinical research fellow at the University of Washington. http://www.reuters.com/article/2013/04/24/us-race-kidney-idUSBRE93N0VZ20130424

 'Geographic variation in black-white differences in end-of-life care for patients with end stage renal disease,' Clinical Journal of the American Society of Nephrology, 11 April 2013. <a href="http://cjasn.asnjournals.org/content/early/2013/04/09/CJN.06780712.abstract?sid=da82db20-a97b-4df7-ace6-0f56d04a29c1">http://cjasn.asnjournals.org/content/early/2013/04/09/CJN.06780712.abstract?sid=da82db20-a97b-4df7-ace6-0f56d04a29c1</a> Noted in Media Watch, 13 August 2012:

- NEW YORK TIMES | Online 6 August 2012 'At the end of life, talk helps bridge a racial divide.' The patient and family are black. And while race should not be relevant at this moment, research tells us otherwise.¹ Blacks are much more likely than whites to elect aggressive care and to decline do-not-resuscitate orders. hospice enrollment is likewise low. http://www.nytimes.com/2012/08/07/health/views/at-the-end-of-life-talk-helps-bridge-a-racial-divide.html? r=1
  - 'Differences in level of care at the end of life according to race,' American Journal of Critical Care, 2010;19(4):335-343. <a href="http://ajcc.aacnjournals.org/content/19/4/335.abstract">http://ajcc.aacnjournals.org/content/19/4/335.abstract</a>

Noted in Media Watch, 4 June 2012:

JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED, 2012;23(1):28-58. 'What influences African American end-of-life preferences?' Many African Americans choose aggressive life-sustaining treatment at the end of life, even if that treatment seems likely to confer great burden with little chance of benefit. The reasons for this are multi-faceted and include knowledge of/access to services, historical mistrust of the health care system, and spiritual beliefs.http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/journal\_of\_health\_care\_for\_the\_poor\_and\_underserved/v023/23.1.wicher.html

## Misconceptions about palliative care

## Why everyone deserves palliative care

THE HUFFINGTON POST | Online OpEd -19 April 2013 - Life is full of surprises, but statisticians tell us that most Americans who make it to age 65 can expect to live to almost 85, and about 1 in 4 will live past 90. Credit goes to improvements in public health, and to medical breakthroughs that have turned diseases such as cancer from death sentences into chronic diseases. One result is millions of older people with multiple chronic illnesses ... who can nonetheless expect to lead long lives. And there's the rub. Now that these conditions typically allow people to live into old age, those same people may find some of their extra years compromised by pain, medical complications, depression, and disability. As Medical Officer of the American Federation for Aging Research, I applaud and advocate for the scientific breakthroughs that make such survival possible. At the same time, as a geriatrician, I see the pain, loss of independence,

and stress among vulnerable and frail elders; I believe it is the duty of all health care providers to acknowledge and address these problems, and make their relief a major focus of treatment. One powerful and important response to this paradox is the fast-growing field of palliative medicine. http://www.huffingtonpost.com/richard-w-besdine-md/palliative-care b 3095190.html

## **Corrections & Clarifications**

Noted in Media Watch (25 March 2013) was 'New palliative care guidelines stress certification, diversity' (p.9), in *Internal Medicine News*. The National Consensus Project for Quality Palliative Care Clinical Practice Guidelines for Quality Palliative Care (3rd edition) can be downloaded at: <a href="http://www.nationalconsensusproject.org/NCP">http://www.nationalconsensusproject.org/NCP</a> Clinical Practice Guidelines 3rd Edition.pdf

## International

## Trust to shut all elderly care homes

U.K. (NORTHERN IRELAND) | *The Belfast Telegraph* – 26 April 2013 – The Northern Health & Social Care Trust has confirmed speculation that it would be stopping the provision of all residential care services in the long-term. A spokeswoman said it will discuss a paper on the Future of Residential Care Services. Health Minister Edwin Poots last month proposed to reduce the number of statutory residential homes by around 50% over the next three to five years as part of the Transforming Your Care programme of reforms. http://www.belfasttelegraph.co.uk/news/localnational/northern-ireland/trust-to-shut-all-elderly-care-homes-29222095.html

1. 'Transforming Your Care: A Review of Health & Social Care in Northern Ireland,' December 2011. http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf

## Ireland's 'National Positive Ageing Strategy'

IRELAND | Department of Health - 24 April 2013 - The ageing of our population from this point onwards will represent one of the most significant demographic and social developments that Irish society has encountered. There is no doubt that this will pose challenges but it will also bring great opportunities. This Government believes that any challenges can be met and opportunities exploited by planning now to ensure that Irish society is an "age-friendly" one in the vears ahead. The National Positive Ageing Strategy provides the blueprint for this planning - for what we can and must do - individually and collectively - to make Ireland a good country in which to grow older in the years ahead. At its core, the Strategy seeks to create a shift in mind-set in how we, collectively and individually, conceptualise ageing and what needs to be done to promote positive ageing. We have a tendency to think of older people as a separate group rather than to recognise that, hopefully, old age will be a phase in all our lives. At a national level, the Strategy seeks to highlight

that ageing is not solely a health issue – it requires a whole of Government response. <a href="http://www.dohc.ie/publications/pdf/National">http://www.dohc.ie/publications/pdf/National</a> <a href="Positive Ageing Strategy English.pdf?direct=1">Positive Ageing Strategy English.pdf?direct=1</a>

# Extract from Ireland's 'National Positive Ageing Strategy'

Nearly 80% of people who die in Ireland each year are over 65 years of age and therefore, end-of-life care is considered as an important public health issue. Research has found that over two-thirds of Irish people expressed a wish to die at home if at all possible. However, of those aged 65 or older who die in Ireland every year, the majority die in acute hospital settings (often in multi-bedded wards) and in private and public long-stay care facilities. Irrespective of the location of death, Irish research has also found that the most important things for people at end of life were to be surrounded by the people they love, to be free from pain and to be able to communicate.

## Older prisoners are fastest-growing part of jail population, says chief inspector

U.K. (ENGLAND & WALES) | The Guardian – 23 April 2013 – Prisoners aged over 60 are now the fastest-growing part of the jail population in England and Wales, the chief inspector of prisons has told MPs. Nick Hardwick told the Commons justice select committee that the prison service had become a significant carer of elderly people but was struggling to meet their social and healthcare needs. The chief inspector revealed that some prisons, such as Leyhill open prison in Gloucestershire, had developed day-centre-type activities and "quieter wings" where older prisoners could escape the "hurly burly" of general prison life. But he warned there was a lack of awareness among prison staff of how they should meet the health and social care needs of a section of the prison population that was less likely to complain or raise problems with staff. <a href="http://www.guardian.co.uk/society/2013/apr/23/older-prisoners-jail-population-inspector">http://www.guardian.co.uk/society/2013/apr/23/older-prisoners-jail-population-inspector</a>

Noted in Media Watch, 11 February 2013:

U.K. (ENGLAND & WALES) | The Guardian – 5 February 2013 – 'Prisons ombudsman: Dying inmates 'inappropriately' handcuffed or chained.' The Prisons & Probation Ombudsman reported restraints such as escort chains and handcuffs were used on the majority of dying prisoners admitted to a hospital or hospice in the last months of their lives since 2007. http://www.guardian.co.uk/society/2013/feb/05/prisons-ombudsman-dying-inmates-restrained

**N.B.** Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at the foot of p.17.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | Herald-Sun (Melbourne) 26 April 2013 'Australia21 report calls for euthanasia protection.' State Governments should immediately legalise voluntary euthanasia to provide safeguards for a practice already happening anyway, an independent panel of experts says.¹ The report by a non-profit body dedicated to analysing complex issues found even though voluntary euthanasia and assisted suicide were unlawful, they occurred "not infrequently" in Australia with no oversight and rarely any prosecutions. It said Australia's laws were "deficient and unequal" as people with the right knowledge or connections could be helped to die while others had to suffer. <a href="http://www.heraldsun.com.au/news/national/euthanasia-can-be-safely-introduced/story-fncynkc6-1226629812089">http://www.heraldsun.com.au/news/national/euthanasia-can-be-safely-introduced/story-fncynkc6-1226629812089</a>
  - The Right to Choose an Assisted Death: Time for Legislation?' Australia21, April 2013. <a href="http://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21">http://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21</a>
     <a href="https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21">https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21</a>
     <a href="https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21">https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21</a>
     <a href="https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21">https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21</a>
     <a href="https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21">https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21</a>
     <a href="https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21">https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21</a>
     <a href="https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21</a>
     <a href="https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21">https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21</a>
     <a href="https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21">https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21</a>
     <a href="https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c922442b1985c21">https://www.australia21.org.au/publications/press\_releases/13/Apr/d15a2c92442b1985c21</a>
     <a href="https://www.australia21.org.au/publications/press\_releases/
- SWITZERLAND | Associated Press 25 April 2013 'Swiss groups fear study undercuts assisted suicide.' Swiss groups that aid people seeking to end their lives say they fear a national research program could lead to stricter rules for assisted suicide. Switzerland has long permitted "passive assisted suicide," where someone can give another person the means to kill themselves provided the helper doesn't personally benefit from the death. Dignitas, EXIT and EX International officials say a five-year government-funded study of people nearing the end of life is biased against assisted suicide and should be made more neutral. The Swiss government dropped a plan to impose stricter rules in 2011, but the groups said they fear the 15 million Swiss francs (\$15.9 million) study could revive opposition to assisted suicide. <a href="http://www.necn.com/04/25/13/Swiss-groups-fear-study-undercuts-assist/landing-nation.html?&apID=b8d917c1026741db9f0c95152820aef7">http://www.necn.com/04/25/13/Swiss-groups-fear-study-undercuts-assist/landing-nation.html?&apID=b8d917c1026741db9f0c95152820aef7</a>
- IRELAND | *The Independent* (Dublin) 24 April 2013 The Supreme Court will give judgment next week on the appeal by terminally ill Marie Fleming against the rejection of her challenge to the blanket ban on assisted suicide. The appeal by 59-year-old Ms. Fleming, who is in the final stages of Multiple Sclerosis, was heard over four days in February. In reserving judgment, the Chief Justice, Ms. Justice Susan Denham, said the case raised "complex and important constitutional issues." <a href="http://www.independent.ie/irish-news/courts/supreme-court-decision-on-marie-fleming-assisted-suicide-next-week-29219459.html">http://www.independent.ie/irish-news/courts/supreme-court-decision-on-marie-fleming-assisted-suicide-next-week-29219459.html</a>

### 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: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

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

# An analysis of knowledge and attitudes of hospice staff towards organ and tissue donation

BMJ SUPPORTIVE & PALLIATIVE CARE | Online - 18 April 2013 - Only a minority of hospice patients eligible to donate tissue and organs choose to do so. Hospice care staff play a key role in discussions about donation, but their willingness to engage in these discussions and their understanding of issues around tissue and organ donation is poorly understood. Staff wishing to donate their organs after death [i.e., study participants] were more likely to be doctors or nurses than healthcare assistants and more likely to have discussed organ or tissue donation with their family. Staff reporting ever having discussed donation with patients had more years' experience and had similarly

discussed donation with their own family. <a href="http://spcare.bmj.com/content/early/2013/04/">http://spcare.bmj.com/content/early/2013/04/</a> 18/bmjspcare-2012-000416.abstract

## Extract from *BMJ Supportive* & *Palliative Care* article

A reluctance to instigate discussions about organ and tissue donation may prevent palliative patients and their families being allowed the opportunity to donate. Sub-optimal knowledge among hospice staff suggests the need for greater liaison between hospice staff, and the organ and tissue donation teams.

Noted in Media Watch, 9 July 2012:

■ END OF LIFE JOURNAL, 2012;2(2). 'The barriers to organ and tissue donation in palliative care.' Discussions about organ/tissue donation are now expected to become part of end-of-life care discussions, when appropriate. It is commonly perceived that terminally ill people are not eligible to donate their organs/ tissues. However, that is not the case. <a href="http://endoflifejournal.stchristophers.org.uk/clinical-review/the-barriers-to-organ-and-tissue-donation-in-palliative-care">http://endoflifejournal.stchristophers.org.uk/clinical-review/the-barriers-to-organ-and-tissue-donation-in-palliative-care</a>

## [U.S.] National assessment of living wills and do not resuscitate orders

BMJ SUPPORTIVE & PALLIATIVE CARE, 2013;3(2):283-284. Concern exists that living wills are misinterpreted and may result in compromised patient safety. 768 faculty and residents at accredited training centres in 34 [U.S.] states responded [to a survey]: 22% denoted "full code" as the code status for a typical living will and 36% equated "full care" with a code status DNR. Adding clinical context improved correct responses by 21%. Specifying code status improved correct interpretation from 28% to 34%. Treatment decisions were either improved 12-17% by adding code status ('full code,' 'hospice care') or worsened 22% ('DNR'). Further research is required to ensure safety, understanding and appropriate care to patients. Misunderstanding of advance directives is a nationwide problem. <a href="http://spcare.bmj.com/content/3/2/283.2.abstract#aff-1">http://spcare.bmj.com/content/3/2/283.2.abstract#aff-1</a>

**N.B.** This issue of the journal includes the abstracts of papers to be presented at an upcoming conference of the International Society of Advance Care Planning & End of Life Care (Melbourne, Australia, 9-11 May). Contents page: <a href="http://spcare.bmj.com/content/3/2.toc#AbstractsACPELabstracts">http://spcare.bmj.com/content/3/2.toc#AbstractsACPELabstracts</a> (Scroll down to 'Abstracts')

#### Of related interest:

AMERICAN JOURNAL OF PUBLIC HEALTH | Online – 18 April 2013 – 'End-of-life care issues: A personal, economic, public policy, and public health crisis.' Advance directive documents are free, legal, and readily available, yet too few Americans have completed one. Initiating discussions about death is challenging, but progress in medical technology, which leads to increasingly complex medical care choices, makes this imperative. <a href="http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2013.301316">http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2013.301316</a>

- JOURNAL OF ADVANCE NURSING | Online 18 April 2013 'Awareness contexts revisited: Indeterminacy in initiating discussions at the end-of-life.' Contrary to the professed ideal of "open" awareness, some participants [in this study] were only partially aware and others wholly unaware that they were likely approaching the end-of-life. They displayed a reluctance to acquire knowledge which would require them to face the imminence of death. http://onlinelibrary.wiley.com/doi/10.1111/jan.12151/abstract
- JOURNAL OF HUMAN BEHAVIOR IN THE SOCIAL ENVIRONMENT, 2013;23(4):462-474. 'A heavenly collaboration: Social workers and churches working to increase advance directive completion among African American elderly.' This article explores how the religious community and social workers can work toward educating this population on the importance of advance directives and empowering them to take the necessary steps at completion if they choose to do so. <a href="http://www.tandfonline.com/doi/abs/10.1080/10911359.2013.772415">http://www.tandfonline.com/doi/abs/10.1080/10911359.2013.772415</a>

## Delivering a digital death

BRITISH MEDICAL JOURNAL | Online – 24 April 2013 – From this summer, National Health Service (NHS) patients in London will be able to add a new function to their mobile phones. A mobile app will give them access to their Coordinate My Care record, a service designed to ensure that people receiving end of life care get appropriate treatment from any health and social care professional they encounter—including respect for any wishes they make about resuscitation or preferences for dying at home rather than in hospital. The app, which will also support mobile working by professionals, is the next planned enhancement for the Coordinate My Care service, which this month went live across London's entire NHS, including an ambulance trust, 34 acute and specialist trusts, and 14 inpatient hospice units. It is a good example of the locally led information technology initiatives that are likely to become the norm in the reformed English NHS. The drawback is that local initiatives can result in duplicated effort and create islands of information that are difficult to exploit more widely, if required. http://www.bmj.com/content/346/bmj.f2528

## Guidance on withholding and withdrawing treatment of sick children to be updated

BRITISH MEDICAL JOURNAL | Online – 24 April 2013 – The Royal College of Paediatrics & Child Health is reviewing its guidance on withholding and withdrawing medical treatment of sick children, amid continuing controversy over a national newspaper story alleging that some sick children have been placed on the Liverpool Care Pathway [LCP]. Simon Newell, the college's vice president for training and assessment, told the British Medical Journal that he did not expect any radical changes to its existing guidance, which was published in 2004 so is due for updating, when it is published in the next few months. But he admitted that the publication is timely, with the LCP and euthanasia having featured recently in the national press. In November 2012 the Daily Mail ran a front page story entitled, 'Now sick babies go on death pathway,' as part of its campaign to expose alleged misuse of the LCP. http://www.bmj.com/content/346/bmj.f2643

Noted in Media Watch, 10 December 2012:

- BRITISH MEDICAL JOURNAL (BMJ) | Online 4 December 2012 'Daily Mail story on care of sick babies was "highly misleading," says BMJ editor.' The BMJ's editor in chief has criticised the Daily Mail for misleading readers by publishing a highly inaccurate article on the care of severely disabled newborn babies that was based on a personal view article in the BMJ.<sup>1,2</sup> It claimed the personal view was evidence that sick children in the National Health Service were being put on the LCP. <a href="http://www.bmj.com/content/345/bmj.e8240">http://www.bmj.com/content/345/bmj.e8240</a>
  - 'Now sick babies go on death pathway: Doctor's haunting testimony reveals how children are put on end-of-life plan,' Daily Mail, 28 November 2012. [Link to article no longer active]
  - 'How it feels to withdraw feeding from newborn babies,' British Medical Journal, 1 November 2012. <a href="http://www.bmj.com/content/345/bmj.e7319">http://www.bmj.com/content/345/bmj.e7319</a>

#### Of related interest:

- BMC PALLIATIVE CARE | Online 25 April 2013 'Evidence-based planning and costing palliative care services for children: Novel multi-method epidemiological and economic exemplar.' Very little is known about the number of children living within any given geographical locality, costs of care, or experiences of children with ongoing palliative care needs and their families. The authors integrated evidence, and undertook and used novel methodological epidemiological work to develop the first evidence-based and costed commissioning exemplar. http://www.biomedcentral.com/content/pdf/1472-684X-12-18.pdf
- ISSUES IN COMPREHENSIVE PEDIATRIC NURSING | Online 19 April 2013 'A consensus for change: Parent and professional perspectives on care for children at the end of life.' Six issues were identified across professional groupings as particularly challenging within the context of caring for children at the end-of-life: truth telling; symptom management; communication with, and relationships between families and professionals; emotional impact, the withdrawal of feeding or treatment and sibling support. Strong resonance was noted between professionals and parents in the emphasis placed on issues related to talking about death (to child and siblings) and decision-making about the withdrawal of treatment. Conversely, late referral to hospice care and lack of services in the community dominated accounts of parents whose children had non malignant conditions, but were not prioritized by professionals. <a href="http://www.ncbi.nlm.nih.gov/pubmed/23600569">http://www.ncbi.nlm.nih.gov/pubmed/23600569</a>
- JOURNAL OF CHILD HEALTH | Online 22 April 2013 'Underlying barriers to referral to paediatric palliative care services: Knowledge and attitudes of health care professionals in a paediatric tertiary care centre in the U.K.' Survey respondents evidenced good knowledge of the principles of palliative care in closed questions, but their attitudes expressed in open-text questions and reported reasons to refer to a palliative care service demonstrated an association of palliative care with death and dying. The authors suggest that the association of palliative care with end of life may be a modifiable factor relevant to late and non-referral and deserving of further investigation and attention in education and training. http://chc.sagepub.com/content/early/2013/02/28/1367493512468363.abstract

### **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.

#### **Links to Sources**

- 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.
- 3. Access to a complete article, in some cases, may require a subscription or one-time charge.
- **4.** If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
- **5.** Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

#### Something Missed or Overlooked?

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

## Caring for a dying patient in hospital

BRITISH MEDICAL JOURNAL | Online – 17 April 2013 – Every year, more than half a million people die in the U.K., and over half of these deaths occur in hospital. Junior doctors are often required to care for dying patients, and assessment and management of these patients are essential skills. The importance of good end of life care, both for the patient and for their family, is increasingly recognised. However, many people dying in hospital continue to have unmet needs, and, in the U.K. more than half of complaints referred to the Healthcare Commission (the Care Quality Commission's predecessor) concerned the care of dying people. Acquisition of the basic skills required to care for people who are dying can improve the patient's and their family's experience of death, as well as the safety, efficiency, and satisfaction of the junior doctor's work. Doctors are notoriously poor at prognosticating, and recognising that a person is dying is a skill that develops over time. In the patient who is close to death, clinical signs such as reduced consciousness level, respiratory changes (e.g., Cheyne-Stokes breathing), and cardiovascular changes (for example, peripheral vasoconstriction) are common. For the patient and his or her family to have time to express their preferences for end of life care, however, recognition of dying must occur earlier. http://www.bmj.com/content/346/bmj.f2174

### Meaning reconstruction in bereavement: Sense and significance

DEATH STUDIES | Online - 22 April 2013 -Recently there has been growing empirical and theoretical attention to the role of meaning in grief, along with increased recognition of the need for more sophisticated definitions of meaning. The present article highlights philosophical issues inherent in the study of meaning and grief, reviews the place of meaning in current theories of grief, and provides a brief overview of the ways that meaning has been operationalized by grief researchers, including sense-making, benefit finding, identity change, and purpose in life. It is argued that, in our focus on the ways mourners make sense of loss, we have neglected an important aspect of meaning: life significance. Life significance is the felt perception that some aspect of one's life experience "matters." The construct is explored as a potentially important outcome of bereavement; mourners may lose life significance along with their lost loved one, or

they may develop new avenues to life significance as they confront mortality and rebuild shattered worldviews. Related literature, such as appreciation of life as a facet of posttraumatic growth, is surveyed for clues as to the role of life significance in grief. <a href="http://www.tandfonline.com/doi/abs/10.1080/07481187.2012.692453">http://www.tandfonline.com/doi/abs/10.1080/07481187.2012.692453</a>

### Economic components of grief

DEATH STUDIES | Online – 22 April 2013 – The [authors'] findings underline the theoretical importance of financial risk factors for anticipating the duration, pattern, and timing of bereavement outcomes. A challenge ... is how to bring understanding of economic components within emotional and practical support for people preparing for death and those who are bereaved. http://www.tandfonline.com/doi/full/10.1080/0748 1187.2012.692456

## Early palliative care referral for the patient who has terminal cancer

JOURNAL OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS | Online – 23 April 2013 – The need for early palliative care (PC) referral and the physician assistant's role in PC is evident, but providers and patients must overcome the barriers that prevent timely referrals and care of terminally ill patients. Different interventions of palliative care can improve patient satisfaction, but satisfaction is not included in the majority of studies as an outcome of PC. Additional research is needed to compare satisfaction as an outcome to PC. In order to provide evidence-based data on patient satisfaction with PC, providers need to increase appropriate and timely referrals to this specialty. <a href="http://www.jaapa.com/early-palliative-care-referral-for-the-patient-who-has-terminal-cancer/article/287998/">http://www.jaapa.com/early-palliative-care-referral-for-the-patient-who-has-terminal-cancer/article/287998/</a>

## One last teaching moment

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online - 24 April 2013 - Critical conversations can arise at any moment in care settings. How we respond can powerfully affect the patient's perception of being heard and supported and may influence the patient's capacity to trust us. Our capacity to respond, often with little time to reflect, prepare, and anticipate the interaction, is governed not by whether we have memorized a script designed to show caring or compassion, but our ability to acknowledge and address, by both verbal and nonverbal means, the patient's vulnerability and need for support, even if we cannot offer any other hope than our presence. We can only do this if we are truly able to acknowledge, access, and engage the human values that are universally needed in such settings: a genuine desire to care and comfort, to respect, to support, and to validate the patient's circumstances and experience. As physicians, we may have difficulty accessing some of these, as to do so requires us to acknowledge and address vulnerability and sense of helplessness in conversations. http://iama.iamanetwork.com/article.aspx?articleID=1681416

## Of related interest:

BMJ SUPPORTIVE & PALLIATIVE CARE, 2013;3(2):221-222. 'Does a background in general practice add to a doctor's ability to communicate in palliative care?' At heart, GPs think that the way you understand what is going on physically, emotionally and socially for a patient, arrives at a diagnosis and also arrives at a collaborative way forward; through clinical examination or tests and through what goes on in a good consultation. Put more simply, GPs should be good at communication, because the culture of the specialty states that good GPs are good communicators. http://spcare.bmj.com/content/3/2/221.extract

# Supporting home care for the dying: An evaluation of healthcare professionals' perspectives of an individually tailored hospice at home service

JOURNAL OF CLINICAL NURSING | Online – 20 April 2013 – Hospice at home services aim to support patients to remain at home, yet there are wide variations in the design of services and delivery. A hospice at home service was developed to provide various components (accompanied transfer home, crisis intervention and hospice aides) that could be tailored to meet the individual needs of patients. Health care professionals reported the impact and value of each of the components of the service, as helping to support patients to remain at home, by individually tailoring care. They also positively reported that support for family carers appeared to enable them to continue coping, rapid access to the service was suggested to contribute to faster hospital discharges, and the crisis intervention service was identified as helping patients remain in their own home, where they wanted to be. <a href="http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2012.04301.x/abstract">http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2702.2012.04301.x/abstract</a>

## A palliative care needs assessment of rural hospitals

JOURNAL OF PALLIATIVE MEDICINE | Online – 22 April 2013 – Significant barriers to integrating palliative care [in rural hospitals] exist: lack of administrative support, mentorship, and access to palliative care resources; inadequate basic knowledge about palliative care strategies; and limited training/skills in palliative care. Respondents [to this survey] (56%) wanted to learn more about palliative care. <a href="http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0574">http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0574</a>

Noted in Media Watch, 1 April 2013:

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

Noted in Media Watch, 14 January 2013:

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

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

#### End-of-life care in India

## End of life care: Should we struggle on, or let go?

MEDICAL JOURNAL ARMED FORCES IN-DIA, 2013;69(1);2-3. Medical science is advancing so rapidly that, presently, most terminally ill patients receive technology driven end of life care. This is widely perceived as excessive and inappropriate use of technology. Numerous studies have found that the medical care of the dying to be unnecessarily prolonged, painful, expensive and emotionally burdensome to both patients and their families. Often the patients themselves are not in a state to consent for withdrawal of life support, the families are reluctant to take the decision, and doctors continue futile treatment out of fear of litigation. Continuation of life support under these circumstances imposes a large financial burden on the families and denies more deserving patients the scarce critical care resources. In this situation, particularly when patient's relations have exhausted their funds, many

corporate hospitals encourage them to opt for discharge against medical advice and arrange transfer to a government hospital. With this questionable practice, they manage to shift the responsibility, avoid sticky situations of uncleared bills, and tout lower mortality figures than the public institutions. An estimated 80% of the population pays for their medical treatment and this seems to be a major factor in "pauperising" many families. http://medind.nic.in/maa/t13/i1/maat13i1p2.pdf

#### **Quotable Quotes**

Life is pleasant. Death is peaceful. It's the transition that's troublesome. American author and biochemist Isaac Asimov (1920-1992)

#### Of related interest:

MEDICAL JOURNAL ARMED FORCES INDIA, 2013;69(1):48-53. 'End of life issues in the intensive care units.' A structured discussion of end-of-life (EOL) issues is a relatively new phenomenon in India. Personal beliefs, cultural and religious influences, peer, family and societal pressures affect EOL decisions. Indian law does not provide sanction to contentious issues such as do-not-resuscitate orders, living wills and euthanasia. Needed is a prospective determination of which patients will benefit from aggressive management and life-support. http://www.mjafi.net/article/S0377-1237(12)00163-3/abstract

Noted in Media Watch, 25 March 2013:

■ ECONOMIC & POLITICAL WEEKLY, 2013;48(11):44-49. 'The high cost of dying.' The cost of the inpatient care of decedents is much higher than that of survivors at all stages of life. The differential is significantly higher for those residing in rural areas, staying longer in hospitals, utilising private health facilities, and suffering from chronic diseases. The difference is due to physicians in private hospitals prescribing more expensive drugs, subjecting patients to more clinical tests, and the higher charges on utilisation of amenities and facilities. <a href="http://www.epw.in/system/files/pdf/2013\_48/11/The\_High\_Cost\_of\_Dying.pdf">http://www.epw.in/system/files/pdf/2013\_48/11/The\_High\_Cost\_of\_Dying.pdf</a>

pg. 14

# Mapping and comparison of palliative care nationally and across nations: Denmark as a case in point

MORTALITY | Online – 22 April 2013 – The formulated goal of mapping palliative care is the development and dissemination of palliative care nationally and internationally. A process of identification and ranking of the development of palliative care and end-of-life care both in Europe and globally has gained momentum over the last 10 years. Overall, Denmark (DK) has obtained relatively low scores in comparative studies. The development of palliative care as a special area of expertise in DK began in the early 1990s. National-level coordination and documentation have only recently been initiated. Taking DK as a case study, this article examines national data and the 2010 Economist Intelligence Unit (EIU) survey, the latter of which in particular aroused political interest in DK. The authors conclude that the national surveys as well as the EIU survey have limited validity in assessing the quality of palliative care and end-of-life care in DK. The same may be assumed to apply to other countries. Increased focus on qualitative methods and local contexts is needed. http://www.tandfonline.com/doi/abs/10.1080/13576275.2013.786034

 'The Quality of Death: Ranking End of-Life-Care Across the World,' Economist Intelligence Unit, July 2010. The Index, which was commissioned by the Lien Foundation of Singapore, measured the current environment for end-of-life care services across forty countries. Denmark was rated 22<sup>nd</sup>. [First noted in Media Watch, 19 July 2010] http://graphics.eiu.com/upload/QOD main final edition Jul12 toprint.pdf

#### Of related interest:

- INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2013;19(4):160=161. 'How can we monitor palliative care? Suggestions from the Latin American Association for Palliative Care.' Access to pain treatment and to palliative care services is limited even in developed countries, as a result of a lack of political will, insufficient education, and overly restrictive regulations on the use of opioid medications. <a href="http://www.ijpn.co.uk/cgibin/go.pl/library/article.html?uid=98248;article=IJPN 19 4 160 161">http://www.ijpn.co.uk/cgibin/go.pl/library/article.html?uid=98248;article=IJPN 19 4 160 161</a>
- SPRINGER PLUS | Online Accessed 28 April 2013 'Patients attended by palliative care teams: Are they always comparable populations?' The authors of this coordinated analytical, observational and prospective study in two Spanish autonomous regions conclude that palliative care teams cover different profiles of patients with regard to their co morbidity, functional, cognitive and symptomatic states. They point that the organization of palliative care services and their experience appears to condition the profile of patients they attend. There is a need of consensus on the basic descriptors for palliative care patients in order to ensure that results will be comparable. <a href="http://www.springerplus.com/content/pdf/2193-1801-2-177.pdf">http://www.springerplus.com/content/pdf/2193-1801-2-177.pdf</a>

## The Kübler-Ross model, physician distress, and performance reporting

NATURE REVIEW: UROLOGY | Online – 23 April 2013 – Physician performance reporting has been proposed as an essential component of health-care reform, with the aim of improving quality by providing transparency and accountability. Despite strong evidence demonstrating regional variation in practice patterns and lack of evidence-based care, public outcomes reporting has been met with resistance from medical professionals. Application of the Kübler-Ross "five stages of grief" model – a conceptual framework consisting of a series of emotional stages (denial, anger, bargaining, depression, and acceptance) inspired by work with terminally ill patients – could provide some insight into why physicians are reluctant to accept emerging quality-reporting mechanisms. Physician-led quality-improvement initiatives are vital to contemporary health-care reform efforts and applications in urology, as well as other medical disciplines, are currently being explored. http://www.nature.com/nrurol/journal/vaop/ncurrent/abs/nrurol.2013.76.html

# Improving end-of-life care in nursing homes: Implementation and evaluation of an intervention to sustain quality of care

PALLIATIVE MEDICINE | Online – 23 April 2013 – Internationally, policy calls for care homes to provide reliably good end-of-life care. The authors undertook a 20-month project to sustain palliative care improvements achieved by a previous intervention. In comparison with the initial intervention, there were increases in a) the proportion of deceased residents with an anticipatory care plan in place; b) the proportion of those with Do Not Attempt Cardiopulmonary Resuscitation documentation in place; and, c) the proportion of those who were on the Liverpool Care Pathway when they died. Furthermore, there was a reduction in inappropriate hospital deaths of frail and elderly residents with dementia. However, overall hospital deaths increased. A lower level of nursing support managed to sustain and build on the initial outcomes. However, despite increased adoption of key end-of-life care tools, hospital deaths were higher during the sustainability project. While good support from palliative care nurse specialists and GPs can help ensure that key processes remain in place, stable management and key champions are vital to ensure that a palliative care approach becomes embedded within the culture of the care home. http://pmi.sagepub.com/content/early/2013/04/19/0269216313480549.abstract

### Inpatient palliative care consultation: Describing patient satisfaction

THE PERMANENTE JOURNAL, 2013;17(1):53-55. This study identified and measured common patterns of patients' positive care experiences during inpatient palliative consultation, and helped better understand how the journey of discovery experienced by both patients and life-care consult teams can be used to improve the quality of care. The codified responses to questionnaires revealed the perspectives of our patients rather than predicting outcomes. Respondents identified six areas of satisfaction: treatment with dignity and respect by the hospital health care team; after life-care planning consultation, patients felt they were better informed of their illness and medical context; 95% of all patients who responded felt their overall experience was excellent; all respondents felt the life-care planning consultation helped them form a treatment plan; all patients who responded believed their cultural beliefs and values were respected; and all responding patients noted that the inpatient palliative care team adequately addressed pain and symptom control. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3627790/

## Assisted (or facilitated) death

Representative sample of recent articles, etc.

- AMERICAN MEDICAL NEWS | Online 22 April 2013 'Cancer center goes public with assisted-suicide protocol.' The ... Seattle Cancer Care Alliance do their best to treat patients who have cancer. For patients whose disease progression cannot be controlled, the University of Washington-affiliated ... center offers palliative care and transition to hospice. For those who seek physician-assisted suicide under state law, the center is prepared to help them with that, too. Providing access to doctor-hastened death is an element of top-notch care for terminally ill patients, the Alliance's clinical leaders argue in a first-of-its-kind published report to outline an organization's physician-assisted suicide protocols and the results for its patients.\(^1\)
  http://www.amednews.com/article/20130422/profession/130429973/2/?utm\_source=rss&utm\_medium=Profession&utm\_campaign=20130422
  - 'Implementing a death with dignity program at a comprehensive cancer center,' NEW ENG-LAND JOURNAL OF MEDICINE, 2013;368(15):1417-1424. [Noted in Media Watch, 15 April 2013] http://www.nejm.org/doi/full/10.1056/NEJMsa1213398

## **Worth Repeating**

# Communicating with Muslim parents: "the four principles" are not as culturally neutral as suggested

EUROPEAN JOURNAL OF PAEDIATRICS, 2009;168(11):1383-1387. The "four principles approach" has been popularly accepted as a set of universal guidelines for biomedical ethics. Based on four allegedly trans-cultural principles (respect for autonomy, non-maleficence, beneficence and justice), it is supposed to fulfil the need of a "culturally neutral approach to thinking about ethical issues in health care." On the basis of a case-history, this paper challenges the appropriateness of communicating in terms of these four principles with patients with a different background. The case describes the situation in which Muslim parents bring forward that their religion keeps them from consenting to end-of-life decisions by non-religious paediatricians. http://www.springerlink.com/content/u11xkt7155204272/fulltext.pdf

## **Media Watch Online**

#### Asia

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

#### **Australia**

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

#### Canada

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

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

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

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

## Europe

HUNGARY I 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: <a href="http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c">http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c</a>

#### International

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

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

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

Barry R. Ashpole Beamsville, Ontario CANADA 'phone: 905.563.0044

e-mail: barryashpole@bellnet.ca