

## **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.

**7 October 2013 Edition | Issue #326**



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

**Compiled & Annotated by Barry R. Ashpole**

**Home deaths: Scroll down to [Specialist Publications](#) and 'Compassionate communities: End-of-life care as everyone's responsibility' (p.10), in *QJM* (Quarterly Journal of Medicine).**

## **Canada**

### **Provincial committee told funding often inadequate**

BRITISH COLUMBIA | Canada.com – 4 October 2013 – B.C. government finance committee members heard funding requests in the millions of dollars ... [during] ... one of 20 stops for the ... Select Standing Committee on Finance & Government Services. Wendy Pratt, Nanaimo Community Hospice executive director, spoke for stable, annualized funding for hospice. Where Victoria Hospice Society, which derives half its budget of more than \$7million from the province, outside Victoria only \$140,000 is available for the other nine hospices. <http://www.canada.com/Provincial+committee+told+funding+often+inadequate/8998321/story.html>

### **Specialist Publications**

**'What do Canadians think of advanced care planning? Findings from an online opinion poll'** (p.7), in *BMJ Supportive & Palliative Care*.

### **Nearly half of Canadians facing major illness struggle financially: Poll**

CTV NEWS | Online – 30 September 2013 – Nearly half of all Canadians facing a major health crisis ... are struggling financially as a result... Forty percent of those who responded [to an online survey] reported feeling financially strapped after a serious health issue or diagnosis, while 53% of 45- to 54-year-olds said they'd been hit hard by unforeseen health-care costs. While most Canadians realize a serious health event could impact their personal finances, only 13% said they had money set aside for such an eventuality. <http://www.ctvnews.ca/canada/nearly-half-of-canadians-facing-major-illness-struggle-financially-poll-1.1476255>

**N.B.** Marketing Research & Intelligence Association is quoted as saying that online surveys cannot be assigned a margin of error because they do not randomly sample the population.

**Updated 7 October 2013**

**Media Watch Online**

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.11.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 4 October 2013 – '**Ottawa leaves right-to-die debate to provinces.**' The federal government will not legalize euthanasia, leaving the matter to the provinces – and possibly the courts – to sort out. Federal Health Minister Rona Ambrose discussed assisted suicide with her provincial counterparts, including a proposal by Québec's Réjean Hébert that would allow physicians to help terminally ill patients die in certain circumstances. Ms. Ambrose reiterated that her government does not plan to change the Criminal Code to make the practice national, but said the provinces are free to debate the issue. <http://www.theglobeandmail.com/news/national/health-minister-urges-legislatures-to-discuss-assisted-suicide/article14707199/>
- NOVA SCOTIA | *Cape Breton Post* (Sydney) – 30 September 2013 – '**A brave government would facilitate doctor-assisted suicide debate.**' Life and death are perhaps the most emotional, divisive issues known to government. They have the capability to drive a wedge into caucus, and they tend to eclipse all other issues a government wants to promote. It is a rare government that would pull the pin on a grenade and toss it into its own nest while it is trying to drive an agenda focused on tax credits, pipelines, trade deals and sound fiscal management. But a brave government would see an issue hurtling down the highway and look beyond the next throne speech, budget and election. We may have hit that point on assisted suicide, with the mix of an aging population and an empowered baby boom generation. Parliament has now spent a generation of futility trying to move this debate onto the political agenda; 9 times in 22 years, parliamentarians have tried ... to bring assisted suicide into the national consciousness. <http://www.capebretonpost.com/Opinion/Columnists/2013-09-30/article-3409982/A-brave-government-would-facilitate-doctor-assisted-suicide-debate/1>

## U.S.A.

### Medical futility

#### Health care: How long should we wait for a miracle?

CALIFORNIA | *The Merced Sun-Star* – 3 October 2013 – In medicine our job is not to squelch another person's hope for a miracle. And while I do not think I have actually seen a miracle, I know others have – or they believe they have. There is no question very, very rare things do happen on occasion. That includes spontaneous remissions from cancer and recovery from illnesses everyone thought was impossible. Are these miracles? I am not sure, but 76% of Americans believe in miracles and herein lies the problem. Do we build a health care system that plans for miracles? How much time and money should we invest in waiting for a medical miracle to occur at the bedside? Medical futility is a term that implies experts, often from different specialties, agree there is no reasonable chance of success from a given treatment. While futility does not include a numerical part of the definition, we might agree that something is medically futile if the

chance of recovery is, say, more than 1 in a million. So, when a person is in intensive care and the only treatments are those considered "medically futile," should families be allowed to insist that hospitals continue to provide all life-sustaining therapies because "there is always a chance a miracle will take place"? <http://www.mercedsunstar.com/2013/10/03/3255640/health-care-how-long-should-we.html>

#### Specialist Publications

'**Barriers to end-of-life care for African Americans from the providers' perspective: Opportunity for intervention development**' (p.8), in *Journal of Hospice & Palliative Medicine*.

'**Racial and ethnic disparities in palliative care**' (p.8), in *Journal of Palliative Medicine*.

Cont.

Noted in Media Watch, 13 June 2011, #205 (p.8):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 6 June 2011 – **'Approaching patients and family members who hope for a miracle.'** A clinical problem may arise when caring for patients or their surrogates who prefer continued aggressive care based on the belief that a miracle will occur, despite a clinician's belief that further medical treatment is unlikely to have any meaningful benefit. [http://www.jpmsjournal.com/article/S0885-3924\(11\)00243-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(11)00243-0/abstract)

### **Why are Latinos not using palliative and hospice care?**

CALIFORNIA | *New America Media* – 2 October 2013 – Without changes, aging Latinos are reaching the end of their lives unprepared spiritually or financially. Some experts believe that the shift needs to happen from within the community, while others say it is a matter of poor cultural sensitivity from service providers. When facing the last days of a person's life, there are many questions, issues and problems (emotional, spiritual and economic) that have to be resolved. Hospice and palliative care services offer relief and respite for patients and caregivers alike. Yet, Latinos, the largest minority in the U.S., are not using these services for many reasons. <http://newamericamedia.org/2013/10/why-are-latinos-not-using-palliative-and-hospice-care.php>

**N.B.** Several articles on America's Latino population and end-of-life care are noted in Media Watch, 29 July 2013, #316 (p.13).

### **New York State is 48th in the nation for home caregiving for the elderly**

NEW YORK STATE | *The Village Voice* (New York) – 1 October 2013 – The American Association for Retired Persons published the results of its caregiver survey, a study of how families and individuals cope with providing care to their elderly relatives. The survey results were astonishing: forty percent of New Yorkers over 50 report working as an unpaid caregiver to a sick or elderly relative. Nearly 70% of those do it without the aid of a home nurse or care worker. State-wide, over 4 million people are unpaid caregivers for ill, frail, or elderly relatives. The expense of that unpaid care adds up to \$32 billion a year, even though the state only allocates \$3 million. [http://blogs.villagevoice.com/runninscared/2013/10/aarp\\_new\\_york\\_elderly.php](http://blogs.villagevoice.com/runninscared/2013/10/aarp_new_york_elderly.php)

Of related interest:

- *U.S. NEWS & WORLD REPORT* | Online – 30 September 2013 – **'Many Americans worry about cost of long-term care: Poll.'** A new Harris Interactive/HealthDay poll finds that more than two-thirds of Americans are anxious and uncertain about how they'll meet nursing home or home care costs should they need them. Most people were also wrong about how most of these costs are covered under the current [health] system. <http://health.usnews.com/health-news/news/articles/2013/09/30/many-americans-worry-about-cost-of-long-term-care-poll>

### **Hospice providers say state Medicaid cuts will mean higher costs**

MICHIGAN | *Crain's Detroit Business* – 29 September 2013 – The Michigan Department of Community Health plans to eliminate Medicaid inpatient hospice room and board funding to 11 hospice programs. The \$2.5 million in projected annual cuts for fiscal 2013-2014 could lead to higher costs to the state as hundreds of terminally ill-patients might require emergency or hospital care in their final days. <http://www.crainsdetroit.com/article/20130929/NEWS/309299983/hospice-providers-say-state-medicaid-cuts-will-mean-higher-costs#>

## International

### Survey reveals working caregivers need more support from employers

SINGAPORE | Channel News Asia – 6 October 2013 – A survey by the labour movement has found that the majority of working caregivers need more support from employers to make their caregiving role easier. It found that on average, caregivers spend 30 hours each week caring for their dependents. Among the working caregivers surveyed, over a quarter or 27% have multiple dependents to care for, such as children, aged parents or family members with special needs. The survey ... found 62% of working caregivers do not receive Flexible Work Arrangement benefits, while 77% said employers do not provide Eldercare Leave. <http://www.channelnewsasia.com/news/singapore/ntuc-survey-reveals/837556.html>

#### Corrections & Clarifications

'Singapore's caregiver crunch' published in *The Straits Times* (Singapore) and noted in *Media Watch*, 30 September 2013, #325 (p.7), refers to a study by researchers at Duke-NUS Medical School. See 'Health impacts of caregiving for older adults with functional limitations: Results from the Singapore Survey on Informal Caregiving,' *Journal of Aging & Health*, 2013;25(6):998-1012: <http://jah.sagepub.com/content/25/6/998>

Noted in *Media Watch*, 24 June 2013, #311 (p.3):

- AMERICAN ASSOCIATION FOR RETIRED PERSONS | Online – 17 June 2013 – '**Demographics, family caregiving demands call for modernizing workplace leave for caregivers.**' A new report argues for improving family leave for working caregivers, citing the growing population of older Americans, increasing numbers of family caregivers on the job, and escalating demands and stress on caregivers.<sup>1</sup> <http://www.aarp.org/about-aarp/press-center/info-06-2013/Demographics-Family-Caregiving-Demands-Call-For-Modernizing-Leave-for-Caregivers-Says-New-AARP-Report.html>

1. *Keeping Up with the Times: Supporting Family Caregivers with Workplace Leave Policies*, American Association for Retired Persons, Public Policy Institute, Washington, June 2013. [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/lrc/2013/fmla-insight-keeping-up-with-time-AARP-ppi-lrc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/lrc/2013/fmla-insight-keeping-up-with-time-AARP-ppi-lrc.pdf)

### Changes proposed to way we deal with our dead

NEW ZEALAND | News Talk ZB (Auckland) – 4 October 2013 – The Law Commission is proposing a major changes for rules around burials and cremations. They include allowing alternative burial providers, including eco or natural burial sites, making funeral providers more transparent and allowing people to bury their loved ones on private land such as a family farm. This is the first time the law surrounding burials funeral and cremation services has been reviewed holistically. <http://www.newstalkzb.co.nz/auckland/news/nbnat/1352120962-changes-proposed-to-way-we-deal-with-our-dead>

#### Barry R. Ashpole



My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

## **Survey shows most people want only "comfort care" but very few have taken steps to ensure their wishes are respected**

U.K. | *The Guardian* – 4 October 2013 – Most people in the U.K. do not want doctors to intervene when they reach the end of their lives beyond making them comfortable, but wrongly believe their family would be able to ensure hospitals did not medicate and resuscitate them, a survey shows.<sup>1</sup> Only about 4% of people have signed an advance decision, which legally binds doctors to carry out their wishes. Without such a directive, the hospital will decide what treatment a person gets at the end of their life if they cannot express their wishes, and not their family. The representative poll of nearly 2,000 people ... found that more than half of adults (57%) would want only what they call "comfort care" at the end of life – measures to ensure the person has no pain or suffering, but no resuscitation or tube feeding. It found that 13% would want limited intervention, which could include some medication and tube feeding and could prolong life. They would not be resuscitated or put on a ventilator. Only 12% would want every possible measure taken to keep them alive. <http://www.theguardian.com/society/2013/oct/04/end-of-life-care-plans-survey>

1. YouGov Survey Results. Commissioned by the charity Compassion in Dying, September 2013. <http://www.compassionindying.org.uk/sites/default/files/YG-Archive-Compassion-in-Dying-results-120913.pdf>

### **End-of-life care in Australia**

#### **Backflip on \$1 million cut to Philip Kennedy Centre hospice which put 29 nursing jobs at risk**

AUSTRALIA (SOUTH AUSTRALIA) | News.com.au – 3 October 2013 – The Philip Kennedy Centre hospice ... has been given a funding lifeline after facing closure at the end of the year. The State Government had cut its \$1 million annual funding to Southern Cross Care to run the 12-bed palliative care facility. The cut also put 28 nursing jobs in jeopardy. Health Minister Jack Snelling announced the backflip saying it would be funded for another year, following public anger over the cost cutting measure. <http://www.news.com.au/national-news/south-australia/snelling-backflip-on-1-million-cut-to-philip-kennedy-centre-hospice-which-put-29-nursing-jobs-at-risk/story-fnii5yv4-1226732224142>

Noted in Media Watch, 30 September 2013, #325 (p.6):

- AUSTRALIA (SOUTH AUSTRALIA) | *The Herald Sun* (Melbourne) – 24 September 2013 – '**Philip Kennedy Centre hospice to close after \$1m state funding cuts.**' The hospice at the Philip Kennedy Centre [the only hospice located within an Australian nursing home] will close by the end of... <http://www.heraldsun.com.au/news/national/philip-kennedy-centre-hospice-to-close-after-1m-state-funding-cuts/story-fnii5yv7-1226726431809>

### **Sweden ranked first for treatment of elderly in UN report**

U.K. | BBC News – 1 October 2013 – Sweden is the best place in the world to be old and Afghanistan the worst, according to a UN-backed global study ... [which] ... examined the quality of life of the elderly in 91 nations.<sup>1</sup> Norway and Germany made up the top spots, with the U.K. in 13th place. The index warns that many countries do not have adequate support in place for their ageing populations. <http://www.bbc.co.uk/news/world-24346962>

1. 'The Global AgeWatch Index 2013: Insight report, summary and methodology,' October 2013. <http://www.helpage.org/global-agewatch/reports/global-agewatch-index-2013-insight-report-summary-and-methodology/>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BELGIUM | *The Sunday Times* (U.K.) – 6 October 2013 – **'Belgium votes on allowing children to opt for euthanasia.'** MPs will debate a sweeping new bill that would extend the country's liberal medical mercy-killing laws to include children and dementia sufferers. Euthanasia on the grounds of "unbearable psychological or physical suffering" has been legal in Belgium since 2002, but a broad coalition of parties is drafting new legislation that would extend the provision to children and those suffering from dementia or other "diseases of the brain."  
[http://www.thesundaytimes.co.uk/sto/news/world\\_news/Europe/article1323761.ece?CMP=OTH-gnws-standard-2013\\_10\\_05](http://www.thesundaytimes.co.uk/sto/news/world_news/Europe/article1323761.ece?CMP=OTH-gnws-standard-2013_10_05)

### Specialist Publications

**'Palliative sedation in Dutch general practice from 2005 to 2011: A dynamic cohort study of trends and reasons'** (p.7), in *British Journal of General Practice*.

**'Belgian general practitioners' perspectives on the use of palliative sedation in end-of-life home care: A qualitative study'** (p.7), in *Journal of Pain & Symptom Management*.

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

#### **Emergency and palliative care nurses' levels of anxiety about death and coping with death: A questionnaire survey**

*AUSTRALASIAN EMERGENCY NURSING JOURNAL* | Online – 30 September 2013 – This study investigates attitudes of emergency and palliative care nurses towards death and dying. Nurses held low to moderate fear of death (44%), death avoidance (34%), escape acceptance (47%), and approach acceptance (59%). Emergency nurses reported higher death avoidance and significantly lower coping skills than palliative care nurses. Both reported high acceptance of the reality of death (neutral acceptance 82%), and indicated they coped better with a patient who was dying than with the patient's family. Nurses generally held positive attitudes towards death and dying. [http://www.aenj.org.au/article/S1574-6267\(13\)00081-5/abstract](http://www.aenj.org.au/article/S1574-6267(13)00081-5/abstract)

Of related interest:

- *NURSING OLDER PEOPLE* | Online – 1 October 2013 – **'How nurses can help ease patient transitions to end of life care.'** Moving from curative to palliative care is often difficult for patients, families and healthcare providers, because hospice or end of life care can be seen as a failure of healthcare teams or as patients having given up. Nurses' role in this transition is to provide care, educate and advocate for patients, and encourage reflection on the implications of end of life. <http://rcnpublishing.com/doi/abs/10.7748/nop2013.10.25.8.22.e479>



 World hospice &  
palliative care day  
Voices for hospices 2013

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

12 October 2013

## **Development and evaluation of the feasibility and effects on staff, patients, and families of a new tool, the Psychosocial Assessment & Communication Evaluation (PACE), to improve communication and palliative care in intensive care and during clinical uncertainty**

*BMC MEDICINE* | Online – 1 October 2013 – PACE provides individualized assessments of all patients entering the ICU. It is completed within 24 to 48 hours of admission, and covers five aspects (key relationships, social details and needs, patient preferences, communication and information status, and other concerns), followed by recording of an ongoing communication evaluation. Implementation is supported by a training program with specialist palliative care. A post-implementation survey of 95 ICU staff found that 89% rated PACE assessment as very or generally useful. Of 213 family members, 165 (78%) responded to their survey, and two-thirds had PACE completed. Those for whom PACE was completed reported significantly higher satisfaction with symptom control, and the honesty and consistency of information from staff ... compared with those who did not. <http://www.biomedcentral.com/content/pdf/1741-7015-11-213.pdf>

Of related interest:

- *RESEARCH IN NURSING & HEALTH* | Online – 30 September 2013 – '**Palliative care communication: Linking patients' prognoses, values, and goals of care.**' This study's aim was to describe the processes of prognostic communication in palliative care goals of care consultations. The authors identified five processes by which clinicians link prognoses, values, and goals of care: 1) signposting the crossroads; 2) closing off a goal; 3) clarifying current path; 4) linking paths and patients' values; and, 5) choosing among paths. <http://onlinelibrary.wiley.com/doi/10.1002/nur.21563/abstract;jsessionid=868D5D40EB9CEB4FBE3589DFDEBA27EB.f01t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

## **What do Canadians think of advanced care planning? Findings from an online opinion poll**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 4 October 2013 – The purpose of this study was to determine the level of engagement of average Canadians in ACP [advance care planning] activities. Respondents were from all provinces of Canada, 52% were women, and 33% were between 45 years and 54 years of age. Of 1,021 national sample respondents, 16% were aware of the term, ACP, 52% had discussions with their family or friends, and 10% had discussions with healthcare providers. Overall, 20% of respondents had a written ACP and 47% had designated a substitute decision maker. Being older was associated with significantly more engagement in ACP activities and there were significant differences in ACP engagement across Canada. <http://spcare.bmj.com/content/early/2013/10/04/bmjspcare-2013-000473.abstract>

## **Palliative sedation in Dutch general practice from 2005 to 2011: A dynamic cohort study of trends and reasons**

*BRITISH JOURNAL OF GENERAL PRACTICE*, 2013;63(615):e669-e675. From 2005-2011, 183 cases were reported from 56 general practices. The incidence ... fluctuated between 33.7 per 100 000 patients in 2006 and 15.2 in 2011. No rise or decline during the period was observed. Palliative sedation was applied in 5.7% of all deaths and most frequently used in younger patients with cancer. <http://www.ingentaconnect.com/content/rcgp/bjgp/2013/0000063/00000615/art00034>

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 3 October 2013 – '**Belgian general practitioners' perspectives on the use of palliative sedation in end-of-life home care: A qualitative study.**' Palliative sedation [PS] home practice deviates from the PS guidelines' recommendations. In addition to the GPs' shortage of knowledge, the guidelines' recommendations do not always meet the particular needs of end of life [EoL] home care. If one consideration of EoL home care is to respect a patient's wish to die at home, then the pre-emptive use of PS to avoid a futile transfer to the hospital ... deserves more attention in the PS debate. [http://www.jpmsjournal.com/article/S0885-3924\(13\)00402-8/abstract](http://www.jpmsjournal.com/article/S0885-3924(13)00402-8/abstract)

## Families and caregivers of older people: Expectations, communication and care decisions

*COLLEGIAN* (Australian Journal of Nursing Practice, Scholarship & Research) | Online – 30 September 2013 – While family caregivers may temporarily relinquish responsibility for daily care to health professionals for the period of hospitalization, new expectations and demands are placed upon them. Family caregivers can be asked to commit to new relationships with health professionals, contribute to care decisions and discharge planning. For the caregivers of older patients these new expectations may be challenging, and contribute to feelings of burden and increased stress. This study found that the burden associated with the experience of caregiving continued despite the hospitalization of their relative. The challenges faced by families included communicating with health professionals, and being asked to contribute to care decisions, in particular those regarding discharge planning, and managing conflict. In conclusion, the issues and challenges faced by family caregivers needs to be acknowledged and considered as an extension of patient care planning. [http://www.collegianjournal.com/article/S1322-7696\(13\)00087-5/abstract](http://www.collegianjournal.com/article/S1322-7696(13)00087-5/abstract)

## Barriers to end-of-life care for African Americans from the providers' perspective: Opportunity for intervention development

*JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 October 2013 – Research has shown that African Americans (AAs) are less likely to complete advance directives and enroll in hospice. Barriers identified included: lack of knowledge about prognosis, desires for aggressive treatment, family members resistance to accepting hospice, and lack of insurance. Providers believed that acceptance of EOL care options among AAs could be improved by increasing cultural sensitivity through education and training initiatives, and increasing staff diversity. Respondents [i.e., interview participants] did not have programs currently in place to increase awareness of EOL care options for underrepresented minorities, but felt that there was a need to develop these types of programs. These data can be used in future research endeavors to create interventions designed to increase awareness of EOL care options for AAs and other underrepresented minorities. <http://ajh.sagepub.com/content/early/2013/10/03/1049909113507127.abstract>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 27 September 2013 – '**Racial and ethnic disparities in palliative care.**' Racial and ethnic disparities in health care access and quality are well documented for some minority groups. However, compared to other areas of health care, such as disease prevention, early detection, and curative care, research in disparities in palliative care is limited. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.9468>

Noted in Media Watch, 13 August 2012, #266 (p.2):

- *THE 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.<sup>1</sup> Blacks are much more likely than whites to elect aggressive care and to also 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) [http://www.nytimes.com/2012/08/07/health/views/at-the-end-of-life-talk-helps-bridge-a-racial-divide.html?\\_r=1](http://www.nytimes.com/2012/08/07/health/views/at-the-end-of-life-talk-helps-bridge-a-racial-divide.html?_r=1)

1. 'Differences in level of care at the end of life according to race,' *American Journal of Critical Care*, 2010;19(4):335-343. <http://ajcc.aacnjournals.org/content/19/4/335.abstract>

Noted in Media Watch, 4 June 2012, 256 (p.10):

- *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 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](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)

## **Role ambiguity, role conflict, or burnout: Are these areas of concern for Australian palliative care volunteers?**

*JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 3 October 2013 – The majority [of survey respondents] were middle-aged women who had been palliative care volunteers for more than 7 years and volunteered [on average] 14 hours/week. They reported low levels of role ambiguity and conflict, and described enjoying their volunteering and having no symptoms of burnout. Self-care strategies and working within a structured volunteer program appear to be important protective factors. <http://ajh.sagepub.com/content/early/2013/10/03/1049909113505195.abstract>

**N.B.** Several articles on different aspects of the work of hospice volunteers are noted in Media Watch, 22 April 2013, #302 (p.7).

## **End-of-life communication: Let's talk about death**

*JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS EDINBURGH*, 2013;43(3): 197-199. Talking about dying with patients is hard, particularly when there has been a long relationship with the patient and the goals of care have changed. But honest conversations, sensitively navigated, will strengthen rather than damage the relationship between doctors and dying patients, allow patients to prioritise and prepare for the future, and reduce suffering in bereavement for those left behind. Doctors need to be equipped with the appropriate knowledge, skills and attitudes to communicate effectively with patients who are dying. But even these attributes are not enough without the provision of time: time to understand preferences, to build trust, to meet loved ones and to break bad news. End-of-life communication is not an event, but a process, ideally built up over days, weeks or

months. In the increasingly time-pressured clinical environment, finding the time for this is likely to become our greatest challenge. <http://www.rcpe.ac.uk/sites/default/files/Sleepman.pdf>

### **Doctors should accept they are no longer primary decision makers in care, says think tank**

*BRITISH MEDICAL JOURNAL* | Online – 3 October 2013 – Doctors have to change their view of themselves as the primary decision makers in care and shift to a partnership model that allows patients to play an active part in determining their own care. The King's Fund claims that it is time for a new approach to caring for people with long term conditions that involves doctors being more proactive and preventive in their approach. <http://www.bmj.com/content/347/bmj.f5972>

## **The dead-donor rule and the future of organ donation**

*NEW ENGLAND JOURNAL OF MEDICINE* | Online – 3 October 2013 – The ethics of organ transplantation have been premised on "the dead-donor rule" (DDR), which states that vital organs should be taken only from persons who are dead. Yet it is not obvious why certain living patients, such as those who are near death but on life support, should not be allowed to donate their organs, if doing so would benefit others and be consistent with their own interests. <http://www.nejm.org/doi/full/10.1056/NEJMp1307220>

Of related interest:

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 3 October 2013 – '**Life or death for the dead-donor rule?**' The increasing disproportion between the supply of donor organs and the demand for transplants as well as the tragic deaths of patients awaiting organs have encouraged the development of creative solutions to increase the donor supply. <http://www.nejm.org/doi/full/10.1056/NEJMp1308078>

Cont.

- *PROCEEDINGS* (Baylor University Medical Center), 2013;26(4):417-422. '**Consults for conflict: The history of ethics consultation.**' The very existence of ethics consultation reflects both the increasing complexity of modern medicine's ethical questions and our discomfort with the prospect of answering them alone. Two developments in the past century were instrumental in driving the development of ethics consultation – organ replacement therapy and intensive care. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3777084/>

Noted in Media Watch, 31 December 2012, #286 (p.6):

- *CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS*, 2013;22(1):55-63. **""Keeping her whole" – Bereaved families' accounts of declining a request for organ donation.**' Currently in the U.K. 10,000 individuals could benefit from an organ transplant, but the shortage of available organs means that 1,000 people die each year while waiting. Relatives of potential organ donors are the most critical link in maintaining organ availability for transplantation, as they must give their explicit consent before organ donation can take place. <http://journals.cambridge.org/action/displayFulltext?type=1&fid=8771561&jid=CQH&volumeld=22&issuelid=01&aid=8771559&bodyld=&membershipNumber=&societyETOCSession=>

### Compassionate communities: End-of-life care as everyone's responsibility

*QJM* (Quarterly Journal of Medicine) | Online – 30 September 2013 – In 2013 a survey of over 200 U.K. palliative care services<sup>1</sup> ... found most of these services were prioritizing "community engagement" initiatives, most commonly adopting a "compassionate community" model. Later this same year, a report by the National Council for Palliative Care and the charity Murray Hall Community Trust described the increasing uptake of compassionate communities by palliative care services in England.<sup>2</sup> This review examines this new policy and practice development in British end-of-life care explaining its conceptual origins and describing its policy importance to current practice. <http://qjmed.oxfordjournals.org/content/early/2013/09/30/qjmed.hct200.short?rss=1>

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#### Media Watch: Editorial Practice

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

#### Distribution

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1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
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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.

1. 'Care of the dying patient in the community,' *British Medical Journal*, 3 July 2013. National and local policies now focus on facilitating home deaths and there has been a small increase in the proportion and absolute number of people dying at home. The focus of end of life care is therefore shifting to the community, where the role of the general practitioner, with support from the community palliative care team, is key. <http://www.bmj.com/content/347/bmj.f4085>
2. 'An Overview of Compassionate Care Communities in England,' Murray Hall Community Trust, National Council for Palliative Care, Dying Matters Coalition, July 2013. [http://conversationsforlife.co.uk/wp-content/uploads/2013/08/CC\\_Report\\_Final\\_July\\_2013.pdf](http://conversationsforlife.co.uk/wp-content/uploads/2013/08/CC_Report_Final_July_2013.pdf)

### Media Watch Online

#### **International**

New

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2013/10/media-watch/>

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

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

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

#### **Asia**

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

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

#### **Australia**

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

#### **Canada**

ONTARIO | Central West Palliative Care Network: [http://cwpcn.ca/Health\\_Practitioners/resources.htm?mediawatch=1](http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1)

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

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

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

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

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/news-events>

#### **Europe**

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

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

## Early palliative care in cancer treatment: Rationale, evidence and clinical implications

*THERAPEUTIC ADVANCES IN MEDICAL ONCOLOGY* | Online – 26 September 2013 – In standard oncology practice, it is easy for focus on ... [palliative] ... care to be obscured by discussions and management of anticancer therapy and adequate attention to quality of life, patient preferences, and goals of care often occur only days to weeks from the patient's death. The initiation of palliative care and discussion of the patients' goals and preferences earlier in the course of disease can lead to improved symptom control, reduced distress throughout the disease-directed therapy, and care delivery that matches the patients' preferences. This review discusses the evolving evidence for early initiation of palliative care in patients with advanced cancer and ongoing barriers to care in this setting. The authors highlight challenges for research and care delivery and the potential for broader awareness of the demonstrated benefits of palliative care... <http://tam.sagepub.com/content/early/2013/09/24/1758834013500375.abstract>

Of related interest:

- *SEMINARS IN CARDIOTHORACIC AND VASCULAR ANESTHESIA* | Online – 26 September 2013 – **'The distinct role of palliative care in the surgical intensive care unit.'** Palliative care enhances the team's ability to recognize pain and distress; establish the patient's wishes, beliefs and values, their impact on decision making; develop flexible communication strategies; conduct family meetings and establish goals of care; provide family support during the dying process; help resolve team conflicts; and establish reasonable goals for life support and resuscitation. <http://scv.sagepub.com/content/early/2013/09/26/1089253213506121.abstract>

## Worth Repeating

### Using the values-based history to fine-tune advance care planning for oncology patients

*JOURNAL OF CANCER EDUCATION* | Online – 16 January 2010 – There is no standardized approach to the discussion of advanced care planning. One approach ... involves the use of a values history ... [which] ... focuses on questions related to overall health, personal relationships, and independence, as well as symptoms. The values history facilitates communication with the patient and allows the patient to express their view. This approach to patient communication is less threatening to patients and does not force the patient into thinking they need the right answer. They are useful in a wide range of situations where the doctor needs to understand the patient as a person. Compared to traditional, medicalized advance directives, values histories are less subject to the objections of not being clearly established at the time of their writing, or

applicable in the circumstances that subsequently arise as in this case. They can help to validate preferences about treatment and also indicate appropriate courses of action that were not, or could not, be covered by traditional advance directives alone. <http://link.springer.com/article/10.1007/s13187-009-0014-0>

#### **Extract from *Journal of Cancer Education* article**

Values-based directives are less intrusive on a doctor's skill in making appropriate clinical decisions. They ask questions that require no technical skill and are easily done by other members of the health-care team.

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