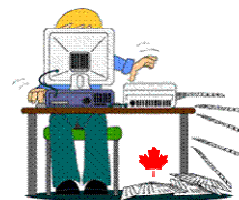


## Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Education and professional development: Scroll down to [Specialist Publications](#) and 'End of life and beyond as hidden curriculum' (p.16), in *Nursing Science Quarterly*.

## Canada

### 96% of Canadians want to choose where they die, poll finds

CBC NEWS | Online – 23 January 2014 – A new Harris/Decima survey has found that the vast majority of Canadians support end-of-life care in the setting of their choice. An online poll commissioned by the Canadian Hospice Palliative Care Association found that 96% of nearly 3,000 respondents want to choose where they die, be it at home, in a long-term care facility or hospital. According to the survey, two thirds of Canadians haven't had discussed end-of-life care options. <http://www.cbc.ca/news/canada/windsor/96-of-canadians-want-to-choose-where-they-die-poll-finds-1.2508304>

#### Extract from CBC News report

Less than half of Canadians – 49% – know that palliative care is even available outside a hospital, long-term care facility or hospice.

### The difficulty in defining death

*THE GLOBE & MAIL* | Online – 19 January 2014 – The questions are often the same, asked in desperate hope that the diagnosis might change: Can't we wait a little longer? How do you know for sure? When Dr. Stephen Beed, critical-care physician at the Queen Elizabeth II Health Sciences Centre in Halifax, has to break the news of a brain death, he understands why families – and even some medical professionals – have a hard time accepting it. Unlike the pale stillness with which death is so often portrayed, their loved ones are warm to the touch, their chests rise and fall, and the line on the EKG [electrocardiogram] continues to bounce. "It looks like they are in a really deep sleep," Beed says, even though an extensive series of tests have confirmed an absence of brain function and brain-stem reflexes. "It doesn't change the reality, but I understand why it's difficult." Uneasiness and confusion about defining death – our fear that "the plug" will be pulled too early, our grief that we may not do right by our loved ones – has become a central point in two very different cases in the U.S.<sup>1,2</sup> <http://www.theglobeandmail.com/life/health-and-fitness/health/the-difficulty-in-defining-death/article16391780/>

Cont.

1. 'Jahi McMath, Ariel Sharon, and the Valley of Death,' *Time Magazine*, 9 January 2014. Today, more and more of us face the uncanny valley of the shadow of death. It's the domain of those, like Jahi [McMath] ... who suffer grievous injury and are kept on this side of life by elaborate and increasingly heroic medical procedures. [Noted in Media Watch, 13 January 2014, #340 (p.1)] <http://content.time.com/time/magazine/article/0,9171,2162277,00.html>
2. 'Texas man wants to end pregnant wife's life support,' United Press International, 23 December 2013. A Texas man said he wants to end life support for his pregnant wife, but state law puts the rights of their 18-week-old fetus above the desires of the mother. [Noted in Media Watch, 30 December 2013, #338 (p.3)] [http://www.upi.com/Top\\_News/US/2013/12/23/Texas-man-wants-to-end-pregnant-wifes-life-support/UPI-59541387805756/?spt=rln&or=1](http://www.upi.com/Top_News/US/2013/12/23/Texas-man-wants-to-end-pregnant-wifes-life-support/UPI-59541387805756/?spt=rln&or=1)

## U.S.A.

### **When elderly are hospitalized, families face tough decisions**

TEXAS | National Public Radio – 24 January 2014 – It's never easy making medical choices for family members who are too sick to speak for themselves. But researchers say families of the elderly should be ready to do so. When people over 65 end up in the hospital, about half of them eventually need someone else in the family to make decisions for them, according to new research.<sup>1</sup> "This has been a growing concern for medicine in the last generation," says Dr. Alexia Torke, who teaches medicine at Indiana University and is a researcher for Regenstrief Institute. "Ever since the advent of intensive care, we've had growing abilities to keep people alive even when they were so sick that they could no longer communicate." And that means family members often have to step in and make difficult calls. Torke says she was surprised at how widespread this experience is. In Torke's study, the decisions that family members had to make ranged from routine to life-or-death. <http://www.npr.org/blogs/health/2014/01/24/265356458/when-elderly-are-hospitalized-families-face-tough-decisions>

1. 'Scope and outcomes of surrogate decision making among hospitalized older adults,' *JAMA Internal Medicine*, 20 January 2014. Decisions are most commonly made by daughters without the help of living wills or previously appointed health care power of attorney forms. <http://archinte.jamanetwork.com/article.aspx?articleid=1813222>

Of related interest:

- RHODE ISLAND | *The Providence Journal* – 19 January 2014 – **'New Rhode Island law aims to ease final days of terminally ill.'** The law has created "Medical Order for Life-Sustaining Treatment," and is only for people whose illness is terminal.<sup>1</sup> A patient or the patient's legal surrogate confers with a doctor, nurse practitioner or physician assistant about the level of care wanted in a various situations. Both the patient and the clinician must sign the order. It then is supposed to travel with the patient into any medical setting. A patient having second thoughts can void it instantly, by writing "void" across the page or simply by telling the staff verbally. And ideally, the form should be updated frequently as circumstances change. Hospitals and nursing homes are required to offer the form to patients upon admission – although, importantly, there is no requirement to fill it out. <http://www.providencejournal.com/news/health/20140119-health-insight-new-r.i.-law-aims-to-ease-final-days-of-terminally-ill.ece>
  1. Medical Order for Life-Sustaining Treatment, Department of Health, State of Rhode Island. <http://www.health.ri.gov/lifestages/death/about/medicalordersforlifesustainingtreatment/>
- STATE OF WASHINGTON | *The Spokesman-Review* (Spokane) – 19 January 2014 – **'Bill before Congress would help with end-of-life decisions.'** The Care Planning Act would provide incentives to primary-care physicians to engage in voluntary discussions with patients surrounding end of life. It behooves all to examine our society's discomfort with the one fate that we cannot escape. It almost feels, at times, in the crush of technology and medical advances, that families have come to consider death an elective procedure, that can be held at bay indefinitely. <http://www.spokesman.com/stories/2014/jan/19/guest-opinion-bill-before-congress-would-help/>

## Hospice techniques for hospitalized patients provide better end-of-life care

ALABAMA | *UAB News* (University of Alabama at Birmingham) – 21 January 2014 – A study by researchers at the Birmingham Veterans Affairs Medical Center [VAMC] and the University of Alabama at Birmingham [UAB] says using home-based hospice practices for terminally ill, hospitalized patients could reduce suffering and improve end-of-life care.<sup>1</sup> The study ... is the first to show that palliative care techniques usually used in a home setting can have an impact on end-of-life care for those who die in a hospital. "More than 75% of Americans say they would prefer to die at home, yet only about 25% do – the vast majority dying in hospitals or nursing homes," said Amos Bailey, director of the Safe Harbor Palliative Care Program at the Birmingham VAMC and professor in the Division of Gerontology, Geriatrics & Palliative Care in the UAB School of Medi-

cine. "This study was designed to see whether home-based hospice practices could be integrated into care in hospitals to improve the end-of-life experience for those who remain hospitalized at time of death." <http://www.uab.edu/news/latest/item/4054-va/uab-study-hospice-techniques-for-hospitalized-patients-provide-better-end-of-life-care>

### Specialist Publications

'Association between palliative case management and utilization of inpatient, intensive care unit, emergency department, and hospice in Medicaid beneficiaries' (p.8), in *American Journal of Hospice & Palliative Medicine*.

1. 'Intervention to improve care at life's end in inpatient settings: The BEACON trial,' *Journal of General Internal Medicine*, 21 January 2014. <http://link.springer.com/article/10.1007/s11606-013-2724-6>

Of related interest:

- PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 19 January 2014 – '**Hospice care in Allegheny County bucks national norm.**' More than 13,000 people a year die in Allegheny County, and data suggest a higher percentage are getting more intensive, personal end-of-life care than is the norm across America. More than half of the county's residents who die receive hospice care before doing so, according to University of Pittsburgh researchers who say America as a whole has yet to reach that threshold. About 53% of those dying in Allegheny County received hospice care. At that time, the rate of hospice utilization in America was around 42%. <http://www.post-gazette.com/news/health/2014/01/20/Hospice-care-in-Allegheny-County-bucks-national-norm/stories/201401200097>

## Law could put South Dakota in cross hairs of life, death decisions

SOUTH DAKOTA | *The Argus-Leader* (Sioux Falls) – 20 January 2014 – In South Dakota as in Texas, you hope that new life and the end of life never converge in the morass of medical, moral and ethical disagreement. But that's what is happening now in Texas.<sup>1</sup> And a law on the books in South Dakota means it could happen here, too. Though the wording is not the same, the law in South Dakota is similar. Unless two physicians determine that it wouldn't help with the development and birth of the child, or that it would be harmful or painful to the woman, "life-sustaining treatment and artificial nutrition and hydration shall be provided

to a pregnant woman," the statute reads. [http://www.argusleader.com/article/20140120/NEWS/301200017/State-law-could-put-S-D-cross-hairs-life-death-decisions?nclick\\_check=1](http://www.argusleader.com/article/20140120/NEWS/301200017/State-law-could-put-S-D-cross-hairs-life-death-decisions?nclick_check=1)

### Specialist Publications

'Legal and ethical responsibilities following brain death: The McMath and Muñoz cases' (p.12), in *Journal of the American Medical Association*.

Cont.

1. 'Texas man wants to end pregnant wife's life support,' United Press International, 23 December 2013. A Texas man said he wants to end life support for his pregnant wife, but state law puts the rights of their 18-week-old fetus above the desires of the mother. [Noted in Media Watch, 30 December 2013, #338 (p.3)] [http://www.upi.com/Top\\_News/US/2013/12/23/Texas-man-wants-to-end-pregnant-wifes-life-support/UPI-59541387805756/?spt=rln&or=1](http://www.upi.com/Top_News/US/2013/12/23/Texas-man-wants-to-end-pregnant-wifes-life-support/UPI-59541387805756/?spt=rln&or=1)

Of related interest:

- *THE CHRISTIAN SCIENCE MONITOR* | Online – 19 January 2014 – **'When does life end? Two emotional cases probe the complexities.'** Teenager Jahi McMath in California and mother Marlise Muñoz in Texas have both been deemed brain-dead, a final state according to statutes. Beyond that determination, however, the cases have taken dramatically different paths and reveal the many complexities involved. <http://www.csmonitor.com/USA/Justice/2014/0119/When-does-life-end-Two-emotional-cases-probe-the-complexities>
- TEXAS | WFAA News (Dallas) – 25 January 2014 – **'Marlise Muñoz to be removed from life support.'** District Judge R.H. Wallace ruled the brain-dead, pregnant mother being kept alive at John Peter Smith Hospital in Fort Worth should be removed from life support. Marlise Muñoz' husband, Erick Muñoz, filed a lawsuit against the hospital seeking to remove life support from his wife. He said Marlise was clear about her wishes not to be kept alive in that state. <http://www.wfaa.com/news/local/Judge-Marlise-Munoz-to-be-removed-from-life-support-241887051.html>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON DC | *Governing* – January 2014 – **""Death with dignity" or "assisted suicide""?** What's in a name? When it comes to "assisted suicide," it turns out quite a lot. Americans are less likely, according to polls, to support a measure legalizing assisted suicide when that phrase is used. That's why advocates for such laws are increasingly using what they say is a more humane description: death with dignity. <http://www.governing.com/topics/health-human-services/gov-death-with-dignity-rhetoric.html>

## International

### End-of-life care in Australia

#### Doctors acknowledge education gap on end of life

*AUSTRALIAN AGEING AGENDA* | Online – 24 January 2014 – Doctors groups have called for urgent investment in training and incentives to address significant concerns over doctors' poor knowledge of advance care planning. The Royal Australian College of General Practitioners said it supported advance care planning becoming a routine part of general practice and it had developed learning resources to help GPs, while the Australian Medical Association said it supported expanding the Practice Incentive Program to include advance care planning. The professional bodies were responding to new research which found significant gaps in doctors' understanding about the legal status of advance care directives and the authority of substitute decision-makers.<sup>1</sup> <http://www.australianageingagenda.com.au/2014/01/24/doctors-acknowledge-education-gap-end-life/>

1. 'Medical practitioners' knowledge and self-reported practices of substitute decision-making and implementation of advance care plans,' *Internal Medicine Journal*, 24 December 2013. [Noted in Media Watch, 20 January 2014, #341 (p.5)] <http://onlinelibrary.wiley.com/doi/10.1111/imj.12354/citedby>

Cont.

Of related interest:

- AUSTRALIA (Victoria) | Special Broadcasting Service (Melbourne) – 20 January 2014 – '**Re-thinking palliative care.**' A Victorian health service is hoping to change the perception that palliative care is only for the end of a patient's life. The newly-launched Culturally Responsive Palliative Care Project is targeting multicultural communities with this message. It is being run by Palliative Care Victoria and the Ethnic Communities' Council of Victoria.<sup>1,2</sup> The project has been launched in the Chinese, Italian, Maltese, Turkish and Vietnamese communities... <http://www.sbs.com.au/news/article/2014/01/20/rethinking-palliative-care>
  1. Palliative Care Victoria, Culturally & Linguistically Diverse Communities: <http://www.pallcarevic.asn.au/multicultural/cald-communities/>
  2. Culturally Responsive Palliative Care Project, Ethnic Communities' Council of Victoria: <http://eccv.org.au/community/media-releases/culturally-responsive-palliative-care-project-gears-up-for-community-education-sessions/>

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

#### **Way cleared for family's challenge over "do not resuscitate" orders**

U.K. (England) | *The Guardian* – 24 January 2014 – Appeal court judges have cleared the way for a family to continue their legal challenge over the way decisions are made not to attempt resuscitation of critically ill patients in England. Relatives of Janet Tracey, who died aged 63 in Addenbrooke's hospital, Cambridge, in 2011, want a national government policy requiring hospitals to consult patients and relatives before they make such decisions ... following a dispute over the way two were handled in her case. A high court judge blocked their first attempt to gain a judicial review in the high court. Justice Nicola Davies said after hearing the facts of the case that such a step would not be appropriate or proportionate. But the court of appeal, in a judgment written by Lord Justice Longmore, and supported by the master of the rolls Lord Dyson and Lord Justice Ryder, ruled that there were "matters of some general importance" in points made by the lawyers acting for David Tracey,

Janet's husband, over consultation and getting a second opinion. The full judicial review hearing will go directly to the appeal court, rather than being heard at the high court first, due to "the very considerable public resources already expended" on the case. <http://www.theguardian.com/law/2014/jan/24/appeal-court-tracey-family-do-not-resuscitate-orders>

#### Specialist Publications

'Prevalence of life-limiting conditions in children and young people in England: Time trends by area type' (p.12), in *Health & Place*.

'Challenges U.K. paramedics currently face in providing fully effective end-of-life care' (p.11), in *International Journal of Palliative Nursing*.

Of related interest:

- U.K. | *Community Care* – 20 January 2014 – '**Care minister "determined" to introduce free end-of-life social care.**' Care [& Support] Minister Norman Lamb has given his backing to free end-of-life social care. An amendment [to the Care Bill] proposes that terminally-ill people be exempted from social care charges to allow them to die in their preferred place. This recommendation was made by the Palliative Care Funding Review.<sup>1</sup> On the review's recommendation, the government set up eight pilot projects to test its proposed funding model. The pilots last two years ... ending in March. <http://www.communitycare.co.uk/2014/01/20/care-minister-determined-introduce-free-end-life-social-care/>
  1. *Funding the Right Care & Support for Everyone: Final Report of the Palliative Care Funding Review* for Secretary of State, July 2011. [Noted in Media Watch, 4 July 2011, #208 (p.4)] [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215107/dh\\_133105.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf)



## Palliative care: International perspective

HUMAN RIGHTS WATCH | *World Report 2014* – 23 January 2014 – *World Report 2014* is the organization's 24th annual review and summarizes key human rights issues in more than 90 countries and territories worldwide, drawing on events from the end of 2012 through November 2013. The report highlights palliative care in several countries:

Palliative care is limited in **Guatemala**, even though more than 10,000 people die of cancer or HIV/AIDS each year, many in severe pain. Although the introduction of immediate release morphine in 2012 was a positive development, the country maintains some of the most restrictive regulations on opioid medications in the world, effectively denying access to essential pain medicines to thousands of patients each year (p.252 of *World Report 2014*).

Tens of thousands of patients face major and often insurmountable obstacles in accessing end-of-life care, even though **Mexican** law grants them a right to such care. Health insurance schemes do not yet adequately address the health needs of incurable patients; drug control regulations unnecessarily restrict access to morphine, an essential medication for severe pain; and training in palliative care for healthcare workers remains insufficient (p.270 of *World Report 2014*).

After a series of positive steps in 2012 to address the suffering of hundreds of thousands of persons with incurable diseases from pain and other symptoms, progress on palliative care in **India** slowed considerably in 2013. The government has so far not allocated a budget to implement India's progressive national palliative care strategy and parliament failed to consider critical amendments to the Narcotic Drugs & Psychotropic Substances Act that would dramatically improve the availability of strong pain medications. More than 7 million people in India require palliative care every year (p.338 of *World Report 2014*).

**Armenia's** complicated and time-consuming prescription and procurement procedures for opioid medications obstruct the delivery of adequate palliative care, condemning most terminally ill patients to unnecessary suffering. Although morphine is a safe, effective, and inexpensive way to improve the lives of terminally ill people, Armenia's current consumption levels of morphine and alternative strong opioid medicines are insufficient to provide care to all terminally ill cancer patients, leaving many without adequate pain relief during the last stages of their illness (p.409 of *World Report 2014*).

Restrictive government policies [in **Russia**] and limited availability of pain treatment persists and severely hinders the delivery of palliative care. Each year, tens of thousands of dying cancer patients are denied their right to adequate pain relief. In May 2013, a doctor in Krasnoyarsk and another woman were found guilty and fined on charges of illegal trafficking of controlled substances, after they helped a man in the final stages of cancer and in debilitating pain obtain opioid pain medicines. In September, an appeals court sent the case for retrial. The court hearing the retrial excluded a lead defense lawyer from the case. A May 2013 government decree somewhat eased patients' access to narcotic pain medications. However, implementation is problematic (p.478 of *World Report 2014*). The government [of the **Ukraine**] took important steps to improve access to palliative care, but has yet to implement new regulations or expand access to opiate substitution treatment for drug users (p.511 of *World Report 2014*).

### WHO boosts hope on pain relief, palliative care

HUMAN RIGHTS WATCH | Online – 24 January 2014 – The World Health Organization has adopted a groundbreaking resolution urging countries to ensure access to pain medicines and palliative care for people with life-threatening illnesses. The resolution addresses the needs of the 20 million people who die each year suffering from moderate or severe pain and other symptoms due to cancer, HIV and other conditions, and the 40 million each year who require palliative care for relief of pain and other symptoms. More than 6.5 million people are estimated to die each year without any access to pain medicines, almost all in low- and middle-income countries. <http://www.hrw.org/news/2014/01/24/un-who-boosts-hope-pain-relief-palliative-care>

### Specialist Publications

'The WHO Collaborating Centre for Public Health Palliative Care Programs: An innovative approach of palliative care development' (p.13), in *Journal of Palliative Medicine*.

World Report 2014: [http://www.hrw.org/sites/default/files/wr2014\\_web\\_0.pdf](http://www.hrw.org/sites/default/files/wr2014_web_0.pdf)

## Dying in the U.K.

### "Can't afford to die": British families on low incomes struggle with "funeral poverty"

U.K. (England & Wales) | *Russia Today* (London Bureau) – 21 January 2014 – Over 100,000 people in the U.K. will hardly manage to pay for a funeral this year. With the average cost of dying having risen by 7.1%, the poor simply cannot afford to pay the costs of funerals, a survey has found.<sup>1</sup> The average cost of dying ... currently stands at £7,622 (\$12,528), a rise of 7.1% in the past year, according to the latest study at the University of Bath's Institute for Policy Research. The cost of dying has steadily increased over recent years in spite of the lowest ever recorded mortality rates for England & Wales. The average cost of a funeral rose by a staggering 80% between 2004 and 2013, however, and the costs of dying are expected to continue to increase over the next five years. <http://rt.com/news/funeral-poverty-afford-die-958/>

1. 'Funeral poverty in the UK: Issues for policy,' University of Bath's Institute for Policy Research, January 2014. <http://www.bath.ac.uk/ipr/pdf/policy-briefs/affording-a-funeral.pdf>

## Elder care in China

### Home-based care way forward for elderly: Shanghai mayor

CHINA | *The Shanghai Daily* – 20 January 2014 – Shanghai is to promote home-based care for seniors to tackle the problem of the city's aging population and the shortage of resources for the elderly, Shanghai Mayor Yang Xiong told the annual session of the Shanghai People's Congress. "The problem is really urgent for the city government as the percentage of the elderly population is increasing by about 2% every year," Yang said. At the end of 2012, Shanghai had 3.67 million residents aged over 60, up 5.6% from a year earlier and a quarter of the total population. Care services can't meet demand, made more acute as 70% of the city's elderly have chronic diseases and need day care or in-home services, an earlier survey found. There are 620 nursing homes in Shanghai with 100,000 beds – enough for just 3% of the city's elderly population. Another problem is that many residents cannot afford fees for in-home care or nursing home services as they receive low government subsidies, said Xu Li, a local lawmaker. <http://www.ecns.cn/2014/01-20/97768.shtml>

### Transformation of Singapore's healthcare model needed

SINGAPORE | *The Strait Times* – 20 January 2014 – Resolving the hospital bed crunch is not just a matter of expanding capacity, but is also about changing Singapore's care model, said Health Minister Gan Kim Yong. This would mean changing the focus to be "less reliant on actual hospital beds, more reliant on community care, as well as home care," Mr. Gan said. One of the ways to do this is to strengthen the primary and long-term care sector, providing patients with alternatives to hospitals when they need medical attention. The bed situa-

tion will remain given our ageing population. <http://www.straitstimes.com/breaking-news/singapore/story/transformation-singapores-healthcare-model-needed-20140120>

#### **Specialist Publications**

'Community initiatives foster health promoting palliative care in Singapore' (p.10), in *European Journal of Palliative Care*.

#### **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.18.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ISRAEL | *Israel Hayom* (Tel-Aviv) – 24 January 2014 – **'Ministerial committee to mull 'death by prescription' bill.'** Amendment to Terminal Patient Law seeks to allow terminally ill patients to ask their doctors to prescribe lethal sedatives to end their suffering, exempting the doctors from criminal liability. [http://www.israelhayom.com/site/newsletter\\_article.php?id=14975](http://www.israelhayom.com/site/newsletter_article.php?id=14975)

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

### **Association between palliative case management and utilization of inpatient, intensive care unit, emergency department, and hospice in Medicaid beneficiaries**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 20 January 2014 – Association between palliative case management (PCM) and the utilization of major health services during the last 30 days of life in Medicaid patients with cancer was assessed... There were 132 PCM enrollees in the intervention group and 54 non-PCM enrollees in the comparison group. The intervention group had lower inpatient admission rate than that of the comparison group, lower ICU admission rate, longer mean hospice days, and lower percentage of persons with death in hospital. No statistically significant differences were found in mean intensive care unit days, treat-and-release emergency department visit rate, or hospice election rate. Palliative case management may reduce hospitalization and increase hospice use in patients nearing death. <http://ajh.sagepub.com/content/early/2014/01/20/1049909113520067.abstract>

### **The practice of palliative care from the perspective of patients and carers**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 16 January 2014 – The emotional experience of care is examined as a practice rather than a topic, acknowledging that patients and carers [i.e., study participants) documented the performance of care and the resulting impact in a variety of situations. The emotional experience of care comprises key aspects of contextual care facilitating autonomy and connectedness. It is embedded in relationships mediated by communication and tenor of care. The perspective of patients and carers places the emotional experience of palliative care centrally. <http://spcare.bmj.com/content/early/2014/01/16/bmjspcare-2013-000551.abstract>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 22 January 2014 – **'Caring at the end of life: Do cancer caregivers differ from other caregivers?'** Informal caregivers perform a critical social and economic role... Cancer caregivers are a proportionally larger cohort than non-cancer caregivers. With the increasing incidence of cancer, the sustainability of a voluntary cancer caregiving workforce will be reliant upon minimising the burden of care. <http://spcare.bmj.com/content/early/2014/01/22/bmjspcare-2013-000495.abstract>
- *EUROPEAN JOURNAL OF CANCER CARE* | Online – 21 January 2014 – **'How does involvement of a hospice nurse specialist impact on the experience on informal caring in palliative care? Perspectives of middle-aged partners bereaved through cancer.'** The aim of this study was to retrospectively explore partners' understandings and experiences in relation to caring for a loved one with a terminal illness, with a particular focus on the role of the hospice nurse specialist (HNS). Five main themes emerged regarding the impact of the HNS on informal caring: "the ambivalence of caring," "the HNS as a 'confidante' in caring," "the HNS as a 'champion' in support," "the work of the HNS – an unseen benefit," and, "being prepared for death and bereavement." Results highlight a crucial need for carers to have a clear understanding of all aspects of the HNS role so that full benefit is derived from their input. <http://onlinelibrary.wiley.com/doi/10.1111/ecc.12183/abstract;jsessionid=3C62CD3B5842DB038A4259F34371A03B.f03t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>



## End-of-life care: Anything but a pathway

*DIABETES & PRIMARY CARE*, 2013;15(6):292-297. Every year, there are about 500,000 deaths in England alone and most of these follow a period of chronic illness such as heart disease, cancer or stroke. Seventy per cent of all deaths occur in people aged 70 years or more, while 58% of deaths occur in hospital, 18% at home, 17% in care homes, and 7% in other settings. Accurate death certification data where diabetes is a contributory factor are not available, but it is estimated that up to 75,000 people with diabetes die annually in England, and therefore the appropriate management of diabetes with agreed actions by individuals and their families is of great importance. People with diabetes have a unique set of care needs during the last year, months and days of life. Until now there has been little guidance on the specific needs of people with diabetes at this time. <http://www.diabetesandprimarycare.co.uk/journal-content/view/end-of-life-care-anything-but-a-pathway>

Noted in Media watch, 9 December 2013, #335 (p.13):

- *PRACTICAL DIABETES*, 2013;30(90):355-356. **"End of Life Diabetes Care: A Strategy Document": Where are we one year on in the light of the review of The Liverpool Care Pathway?** An abstract or a link to the article is only available with the purchase of a subscription. <http://onlinelibrary.wiley.com/doi/10.1002/pdi.1810/abstract>

**N.B.** End of Life Diabetes Care: A Strategy Document Commissioned by Diabetes U.K., July 2012. <http://www.leicestershirediabetes.org.uk/uploads/123/documents/End%20of%20Life%20Diabetes%20Care%20Stategy%20Document%20Final%20170712.pdf>

Of related interest:

- *JOURNAL OF RENAL CARE* | online – 18 January 2014 – **'Pathways to palliative care for patients with chronic kidney disease.'** Loss of function, particularly from stroke, and severe pain are interpreted as representing levels of suffering which would justify the need to withdraw from renal replacement therapy. Family and/or patient indecision complicates and disrupts end-of-life care planning and can establish a cycle of ambiguity. Whilst renal healthcare professionals support early discussion of end-of-life care at pre-dialysis education, congruity with the patient and family when making the final decision is of great importance. <http://onlinelibrary.wiley.com/doi/10.1111/jorc.12049/abstract>

## End-of-life preferences and presence of advance directives among ethnic populations with severe chronic cardiovascular illnesses

*EUROPEAN JOURNAL OF CARDIOVASCULAR NURSING* | Online – 15 January 2014 – The purpose of this study was to explore end-of-life preferences and determine the presence of signed end-of-life advanced directives. Five themes emerged: a) the importance of family involvement in care; b) being pain free (or pain controlled); c) having a comfortable environment for death; d) wanting no procedures for prolonging life; and, e) desiring a relationship with a professional for end-of-life decision making (reported as inconsistently available). Training in end-of-life care should include sensitivity to ethnic and cultural preferences, and com-

petencies in interviewing on sensitive topics. <http://cnu.sagepub.com/content/early/2014/01/15/1474515113519523.abstract>

### Extract from *European Journal of Cardiovascular Nursing* article

New unique findings were related to concerns about multiple and repeatedly rotating professionals not allowing these ethnic patients end-of-life discussions and fear that signing forms would lead to deportation.

Cont.

Of related interest:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2014;20(1):9-14. '**Clinical nurse specialists perspectives on advance care planning conversations: A qualitative study.**' Advance care planning [ACP] required the clinical nurse specialists to "walk a tightrope," balancing potential harm with purported benefit. The decision to introduce an ACP discussion was influenced by three key factors: 1) an assessment of the patient's readiness to discuss the topic; 2) their physical condition; and, 3) the nurse's relationship with the patient and family. [http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=102852;article=IJPN\\_20\\_1\\_9\\_14](http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=102852;article=IJPN_20_1_9_14)

### **Dementia at the end of life: What can hospices do?**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(1):6-10. The needs of people dying with dementia are commonly unmet. Willow Wood Hospice in Lancashire [England] has set up a dementia service, run by a specialist nurse, to start addressing those needs. Issues that commonly affect people with advanced dementia and their carers are: lack of support from health services; concerns regarding reduced food and fluid intake; undetected or untreated pain; and unnecessary and distressing hospital admissions. Professional and family carers need help to recognise when the end of life is approaching. Once this step has been taken, goals of care can be changed, a palliative care philosophy can be adopted and, crucially, advance care planning can be discussed. A specialist dementia team working from a hospice base is well positioned to help improve the lives of people with dementia and those caring for them as the end of life approaches

**N.B.** Access to the *European Journal of Palliative Care* requires a subscription:  
<http://www.haywardpublishing.co.uk/ejpc.aspx>

### **Community initiatives foster health-promoting palliative care in Singapore**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(1):27-29. Despite being universal human experiences, death and dying remain taboo subjects in both Asian and Western societies. In Singapore, the population is aging fast and the need for palliative care is thus increasing. Progress has been made with the launch of a national palliative care strategy in 2012. Health-promoting palliative care (HPPC) provides a useful model to help promote a culturally sensitive public discourse about death, dying and community involvement. In Singapore, several initiatives and community actions reflecting the principles of HPPC have been launched. These could help Singaporeans to better deal with death and dying in a culturally and religiously sensitive way.

### **More palliative care involvement is needed for transplant patients**

*EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(1):30-33. Patients who have already received a transplant, as well as those who are on a waiting list for an organ transplant, have large unmet needs for high-quality palliative and end-of-life care. At Harefield Hospital, a major U.K. cardiothoracic surgery centre, all patients assessed for suitability for lung transplant are offered a holistic assessment by the supportive and palliative care team. To improve transplant patients' quality of life, there is a need to move towards the early involvement of supportive and palliative care and full integration into the multidisciplinary transplant team.

Noted in Media Watch, 8 July 2013, #313 (p.10):

- *PULMONARY & RESPIRATORY MEDICINE* | Online – 24 June 2013 – '**Barriers to the provision of optimal palliative care in a patient awaiting lung transplantation.**' This case report describes palliative and end of life care in a patient with end stage pulmonary fibrosis listed for lung transplantation and discusses the transition from curative restorative care and palliative care to end-of-life care. The goals of care of patients waiting for lung transplantation should be reviewed regularly and clarified as the clinical condition of the patient changes. <http://www.omicsonline.org/2161-105X/2161-105X-3-151.pdf>

## Awareness of impending death for residents of long-term care facilities

*INTERNATIONAL JOURNAL OF OLDER PEOPLE NURSING* | Online – 17 January 2014 – In this mixed methods study, data were collected in three long-term care facilities in Canada. Despite an awareness that death occurs naturally at the end of a long life and/or long illness, a serious decline towards death was not noticed or acknowledged until the last few hours or days of life, thus limiting palliative care to late-stage pain and symptom management. Although this late-stage awareness of impending death is arguably the first necessary step for a change in nursing homes to a palliative-oriented approach to care for people who are nearing death in late life, timely acknowledgement of the potential for death is needed to facilitate improvements in care for residents of long-term facilities. <http://onlinelibrary.wiley.com/doi/10.1111/opn.12045/abstract>

Noted in Media Watch, 17 December 2012, #284 (p.8):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 December 2012 – **'A systematic review of the prevalence of signs of impending death and symptoms in the last 2 weeks of life.'** Twelve articles ... in multiple settings were analyzed. Of the 43 unique symptoms, those with the highest prevalence were: dyspnea (56.7%), pain (52.4%), respiratory secretions/death rattle (51.4%), and confusion (50.1%). Overall prevalence may be useful in anticipating symptoms in the final days and in preparing families for signs of impending death. <http://ajh.sagepub.com/content/early/2012/12/10/1049909112468222.abstract>

Of related interest:

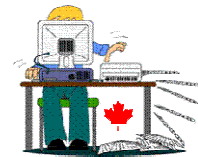
- *NURSING SCIENCE QUARTERLY*, 2014;27(1):20-22. **'The ethics of waiting and anticipating life beyond.'** The author offers a discussion of potential definitions, meanings, and straight thinking responsibilities for healthcare professionals, as they provide professional services with persons and families who may be arduously experiencing the phenomenon of waiting with ever-changing health situations. <http://nsq.sagepub.com/content/27/1/20.abstract>

## Challenges U.K. paramedics currently face in providing fully effective end-of-life care

*INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2014;20(1):37-44. Paramedics play an integral part in community end-of-life care (EoLC) in the U.K., especially given the lack of out-of-hours cover by palliative care specialists. Despite this, there remain multiple barriers to their fully effective provision of such care. This article ... highlights some of the barriers to effective paramedic EoLC provision and introduces examples of collaborative work in the U.K. that aim to overcome these. Given the similarities in the international evolution of paramedic education, readers from other countries will be able to relate to these findings. [http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=102856;article=IJPN\\_20\\_1\\_37\\_44](http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=102856;article=IJPN_20_1_37_44)

### [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>



### [Media Watch posted on Palliative Care Network-e Website](#)

Palliative Care Network-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, exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

## Legal and ethical responsibilities following brain death: The McMath and Muñoz cases

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 24 January 2014 – Death is imbued with social, cultural, and religious meaning. From a legal and scientific perspective, however, death is a definable event. A patient's death makes it possible, even obligatory, to cease treatment and enables the harvesting of organs for transplantation to extend life for others. The clear line between life and death is important because physicians will not squander scarce medical resources or violate medical ethics by imposing treatment after the patient is dead. With a clear diagnosis, family members can also accept the death of a loved one and begin the process of mourning. The concept of *coma dépassé* ("a state beyond coma") emerged in 1959, followed in 1968 by an *ad hoc* Harvard Medical School committee's classic definition of "irreversible coma as a new criterion for death." In 1981, a presidential commission solidified clinical and ethical recognition of brain death defined by neurologic criteria. In 1981, the National Conference of Commissioners on Uniform State Laws approved the Uniform Determination of Death Act, which defined brain death consistently with the president's commission. All states have followed the model act, although 2 states – New Jersey and New York – require hospitals to consider the family's religious or moral views in determining a course of action after brain death. Clinicians, except in these 2 states, do not have to consult the family before withdrawing ventilation. Although state statutes do not specify clinical criteria, the medical literature has carefully described the clinical neurologic examination. <http://jama.jamanetwork.com/article.aspx?articleid=1818922>

## "Being a presence": The ways in which family support workers encompass, embrace, befriend, accompany and endure with families of life-limited children

*JOURNAL OF CHILD HEALTH CARE* | Online – 23 January 2014. Children with life-limiting and disabling conditions are surviving longer than previously, and many require palliative and supportive care, usually at home. Home-based care can put family life under considerable strain, as parents care for their child's complex, often unpredictable, continuing care needs. Rainbow Trust Children's Charity aims to bridge gaps in services for children with life-threatening or terminal conditions by providing family support workers (FSWs). Thematic analysis [in this study] revealed how the FSWs became a presence in families' lives in three main ways: 1) encompassing and embracing families through supporting needs and promoting resilience; 2) befriending and bonding through developing knowledge, trusting relationships and a sense of closeness; and; 3) accompanying and enduring by "being with" families in different settings, situations and crises and by enduring alongside the families. The study demonstrated the fundamental importance of workers who are able to provide aspects of support that is usually not provided by other services. <http://chc.sagepub.com/content/early/2014/01/20/1367493513516391.abstract>

Of related interest:

- *HEALTH & PLACE* | Online – 15 January 2014 – '**Prevalence of life-limiting conditions in children and young people in England: Time trends by area type.**' Recent research determined the prevalence of LLCs [life limiting conditions] in children in England was double previous estimates. Prevalence is highest for children aged less than one year but time trends show no increase for the youngest age group but significant increases for older children. These increases are mirrored by a decrease in all cause mortality for children suggesting improved survival. Rates are highest in more deprived areas and those typified by multicultural populations. <http://www.sciencedirect.com/science/article/pii/S1353829214000033>

## **Building a committed hospice volunteer workforce: Do variables at the experience stage matter?**

*JOURNAL OF COMMUNITY & APPLIED SOCIAL PSYCHOLOGY* | Online – 16 January 2014 – This study ... focuses on hospice volunteers' commitment. Starting from the assumption variables at the experience stage of volunteerism may be relevant in predicting volunteer commitment, questionnaire data on volunteers' motives, motive fulfilment, and role identity were collected in a sample of hospice volunteers. Analyses show positive relationships between altruistic motive fulfilment and a volunteer role identity on the one hand and volunteer commitment on the other. <http://onlinelibrary.wiley.com/doi/10.1002/casp.2182/abstract;jsessionid=079358F298166DFC898688639F873336.f04t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Representative sample of articles on hospice volunteers noted in past issues of Media Watch:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 18 July 2012 – **'Holding on to what you have got: Keeping hospice palliative care volunteers volunteering.'** The items that received the highest mean importance ratings [in this study] included enjoying the work they do, feeling adequately prepared/trained, and learning from their patients' experiences/listening to their patients' life stories. [Noted in Media Watch, 23 July 2012, #263 (p.6)] <http://ajh.sagepub.com/content/early/2012/07/16/1049909112453643.abstract>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 January 2012 – **'Should I stay or should I go: A study of hospice palliative care volunteer satisfaction and retention.'** In five of the nine programs [studied], volunteers said that feeling appreciated by the patients/families they support gave them great satisfaction. Boundary issues and/or role ambiguities were among the least satisfying aspects of their work, mentioned by volunteers in four programs. [Noted in Media Watch, 16 January 2012, #236 (p.5)] <http://ajh.sagepub.com/content/early/2012/01/04/1049909111432622.abstract>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 10 February 2011 – **'Boundary issues for hospice palliative care volunteers...'** The authors distinguish between "definite boundary issues" (things that volunteers should never do, e.g., "accept money from a patient or family"), "potential boundary issues" (things that volunteers should stop and think twice about doing, e.g., "accept a gift from a patient or family"), and "questionable boundary issues" (things that volunteers should be aware of doing, e.g., "give your home phone number to a patient or family"). [Noted in Media Watch, 14 February 2011, #188 (pp.6-7)] <http://ajh.sagepub.com/content/early/2011/02/08/1049909110397926.abstract>

## **The WHO Collaborating Centre for Public Health Palliative Care Programs: An innovative approach of palliative care development**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 January 2014 – The designation of the Catalan Institute of Oncology (Barcelona, Spain) as World Health Organization (WHO) Collaborating Centre for Public Health Palliative Care Programmes (WHOCC-ICO) in February 2008 turns the institution into the first ever center of international reference in regards to palliative care implementation from a public health perspective. The center aims to provide support to countries willing to develop palliative care programs, to identify models of success, to support WHO's policies, and to generate and spread evidence on palliative care. This article describes the WHOCC-ICO's contribution in the implementation of public health palliative care programs and services. Based on new evidence, the center has recently decided to expand its scope by adopting a community-wide chronic care approach which moves beyond cancer and focuses on the early identification of patients with any chronic disease in need of palliative care. Moreover, the center advocates the development of comprehensive models of care that address patients' psychosocial needs. This center's new work plan includes additional significant innovations, such as the start-up of the first chair of palliative care in Spain. Such a whole new approach responds to the main challenges of current palliative care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0203>

Cont.



Representative sample of articles on palliative care from a public health perspective noted in past issues of Media Watch:

- GOVERNMENT HEALTH IT | Online – 11 November 2013 – **'American Public Health Association seeks to improve and rebrand public health.'** The American Public Health Association is envisioning public health models of palliative care that incorporate patient centered medical home design, investments in the palliative care workforce, and public education campaigns. [Noted in Media Watch, 18 November 2013, #332 (p.3)] <http://www.govhealthit.com/news/improving-and-rebranding-public-health>
- JOURNAL OF PALLIATIVE MEDICINE | Online – 20 November 2013 – **'Few U.S. public health schools offer courses on palliative and end-of-life care policy.'** Palliative care has been identified by the World Health Organization as a critical policy element for the relief of suffering, yet palliative care policy receives minimal attention in mainstream U.S. public health journals, conferences, or textbooks. [Noted in Media Watch, 25 November 2013, #333 (p.14)] <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0161>
- PROGRESS IN PALLIATIVE CARE | Online – 3 December 2013 – **'Bereavement and palliative care: A public health perspective.'** In recent years there has been an increasing emphasis placed upon public health perspectives that place palliative care in the context of end-of-life care services across whole populations. However, there is little corresponding public health interest in bereavement. [Noted in Media Watch, 16 December 2013, #336 (p.16)] [http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney\\_ppc183](http://www.ingentaconnect.com/content/maney/ppc/pre-prints/content-maney_ppc183)

### Does withdrawing life-sustaining treatment cause death or allow the patient to die?

MEDICAL LAW REVIEW | Online – 12 January 2014 – This article discusses recent arguments of Franklin Miller and Robert Truog about withdrawal of life-sustaining treatment and causation.<sup>1</sup> The authors argue that traditional medical ethics, and the law, are mistaken to take the view that withdrawal merely allows the patient to die, rather than causing the patient's death, describing such a view as "patently false." They argue that the law's continued position to the contrary stems from a moral bias, resulting in the moral and legal fiction that withdrawal does not cause death but lets the patient die. In so arguing, Miller and Truog join a long line of academic criticism of the law that extends back to the seminal decision of *Airedale National Health Service Trust v Bland* [1993] ... and beyond. The author of this article takes issue with these claims ... [and] ... argues that there are reasonable grounds upon which traditional medical ethics and the law can regard withdrawal of life-sustaining treatment as allowing the patient to die rather than causing death, and so the authors' claims that such a view is patently false cannot be sustained. He then teases out the implications of his conclusions for the claim by Miller and Truog that there is not such a great distinction between withdrawal of life-sustaining treatment, euthanasia, and assisted dying. <http://medlaw.oxfordjournals.org/content/early/2014/01/15/medlaw.fwt034.abstract>

1. *Death, Dying, and Organ Transplantation: Reconstructing Medical Ethics at the End of Life*, Oxford Scholarship Online, January 2012. <http://www.oxfordscholarship.com/view/10.1093/acprof:oso/9780199739172.001.0001/acprof-9780199739172>

Of related interest:

- BRITISH MEDICAL JOURNAL | Online – 20 January 2014 – **'Doctors should care for people who choose to die by starvation, says Dutch Medical Association.'** Elderly people who deliberately choose to stop eating and drinking in order to die more quickly have a right to the appropriate care from their doctor. The association said that only on limited occasions may doctors refer such patients to other carers on the grounds of conscience. It said that treatment must then continue until the referral. The "concept guidelines" currently being considered by the association's members accepted that the withdrawal of food and fluids could be a humane way to die, on the basis of scientific literature. <http://www.bmj.com/content/348/bmj.g331>

Cont.



- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online - '**Are physicians' estimations of future events value-impregnated? Cross-sectional study of double intentions when providing treatment that shortens a dying patient's life.**' The aim of the present study was to corroborate or undermine a previously presented conjecture that physicians' estimations of others' opinions are influenced by their own opinions. The authors used questionnaire based cross-sectional design and described a situation where an imminently dying patient was provided with alleviating drugs which also shortened life and, additionally, were intended to do so. We asked what would happen to physicians' own trust if they took the action described, and also what the physician estimated would happen to the general publics' trust in health services. <http://link.springer.com/article/10.1007/s11019-014-9546-0>

### Research at the end of life: A sacred undertaking

*NURSING SCIENCE QUARTERLY*, 2014;27(1):12-13. Conducting research at the end of life is currently a priority for the [U.S.] National Institute of Nursing Research, the Institute of Medicine, and the National Institute of Health. However, attempting to do research with those who are dying is fraught with numerous challenges. In this column, the author discusses some of the issues and presents viable solutions, so that we as the research community can inform clinicians about care at the end of life and improve quality. <http://nsq.sagepub.com/content/27/1/12.abstract>

Of related interest:

- *NURSING SCIENCE QUARTERLY*, 2014;27(1):14-19. '**Conducting end-of-life research: Strategies for success.**' Conducting studies at the end of life is often challenging for researchers due to the sensitive nature of the research, the vulnerability of the participants and the inherent methodological complexities. Methodological challenges include identifying and gaining access to eligible research participants, estimating the duration of patient survival time in the study, minimizing the potential burden of data collection, and attending to issues of consent and confidentiality. <http://nsq.sagepub.com/content/27/1/14.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.

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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.

## End of life and beyond as hidden curriculum

*NURSING SCIENCE QUARTERLY*, 2014;27(1):23-28. End-of-life experiences are unique. Most can vividly recall feelings during those times. Governing boards in the U.S. attempt to guide nursing faculty regarding end of life curriculum. Yet, the beliefs of faculty members arising from those unique experiences can alter the tone and message of what students are actually taught – often surfacing as hidden curriculum. The authors discuss hidden curriculum, presenting the beliefs regarding end of life of four nursing faculty members... Heightened awareness and respect for the beliefs of all faculty members within any university setting is imperative in decreasing the development of hidden curriculum. <http://nsg.sagepub.com/content/27/1/23.abstract>

Of related interest:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2014;20(1):27-35. **'Three approaches to delivering end-of-life education to care homes in a region of south east England.'** Details of how each approach was operationalised and the initial results and evaluations are discussed. It is essential educators working in the same geographical area communicate and build on one another's contributions. This article is an instance of such collaboration. [http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=102855;article=IJPN\\_20\\_1\\_27\\_35](http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=102855;article=IJPN_20_1_27_35)

## Experiences of sexuality and intimacy in terminal illness: A phenomenological study

*PALLIATIVE MEDICINE* | Online – 21 January 2014 – When someone is living with a life-limiting illness, their coupled relationship is also dying. In their being-towards-death-of-the-couple, patients and partners of patients with motor neuron disease and terminal cancer experienced connecting and disconnecting within their coupled relationship. Becoming-apart-as-a-couple was experienced as loss of spontaneity, as lack of reciprocity and as rejection. This was influenced by a range of factors including medical treatments, disfigurement and the disabling effects of equipment. Some participants experienced re-connecting through becoming-closer-as-a-couple, although this was not always sustained. The ethos of holistic care requires palliative care professionals to provide opportunities for patients and their partners to discuss any concerns they might have about their coupled relationship and to understand the meanings symptoms have for them. <http://pmj.sagepub.com/content/early/2014/01/20/0269216313519489.abstract>

Noted in Media Watch, 1 April 2013, #299 (p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 March 2013 – **'An integrative review of sexual health issues in advanced incurable disease.'** The loss of sexual health can impact a person's overall quality of life and well-being. Studies regarding the sexual health of patients with life limiting illnesses are generally narrative reviews, expert opinions, or exploratory in nature. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0416>

Noted in Media Watch, 27 September 2010, #168 (p.10):

- *NURSING STANDARD*, 2010;24(52):35-39. **'Importance of sexual needs assessment in palliative care.'** Guidance states to support and improve the lives of adults with life-limiting illness, health professionals must address care in the social, psychological, spiritual and physical domains, yet no mention is made of the sexual domain. Palliative care aims to be holistic yet evidence suggests that sexuality is often overlooked when assessing care needs. <http://nursingstandard.rcnpublishing.co.uk/resources/archive/GetArticleById.asp?ArticleId=7954>

Noted in Media Watch, 27 September 2010, #168 (p.10, under 'Worth Repeating'):

- *ADVANCES IN CONTEMPORARY PALLIATIVE & SUPPORTIVE CARE*, 2007;27(1):49-60. **'Let's talk about sex: Risky business for cancer and palliative care clinicians.'** Patient sexuality and intimacy is largely medicalised so that health professional discussions remain at the level of patient fertility, contraception, erectile or menopausal status. <http://www.atypon-link.com/EMP/doi/abs/10.5555/conu.2007.27.1.49>

## Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *NEW YORK LAW SCHOOL LAW REVIEW*, 2013/2014;58:371-389. **'Context matters: Disability, the end of life, and why the conversation is still so difficult.'** Recognizing that the lived experience of people with disabilities often includes negative encounters and discrimination in the health care system may help to explain why conversations about expanding choice-in-dying laws are so difficult for many disability advocates. The fierce opposition by disability advocates to laws that would expand choice in dying will likely continue so long as such laws depend upon a health care system that has not proven itself trustworthy. Developing an inclusive health care system in which all participants deeply understand disability-related issues and work together against disability discrimination will help engender the trust necessary for a system that provides options at the end of life. At minimum, that understanding will help make room for constructive conversation by bringing disability advocates to the table. [http://www.nylslawreview.com/wordpress/wp-content/uploads/2014/01/NYLS\\_Law\\_Review.Volume-58\\_Issue-2.Ouellette-article.pdf](http://www.nylslawreview.com/wordpress/wp-content/uploads/2014/01/NYLS_Law_Review.Volume-58_Issue-2.Ouellette-article.pdf)
- *PHILOSOPHY, ETHICS & HUMANITIES IN MEDICINE* | Online – 15 January 2014 – **'Should assisted dying be legalised?'** The Universities of Oxford and Cambridge held the 2013 Varsity Medical Debate on the motion "This House Would Legalise Assisted Dying." This article summarises the key arguments developed over the course of the debate. The authors explore how assisted dying can affect both the patient and doctor; the nature of consent and limits of autonomy; the effects on society; the viability of a proposed model; and, perhaps most importantly, the potential need for the practice within our current medico-legal framework. <http://www.peh-med.com/content/pdf/1747-5341-9-3.pdf>

## Worth Repeating

### Too many check boxes, too little narrative

*MEDSCAPE* | Online – 13 September 2013 – What's going on with the patient? The ability to read a patient's "story" is highly valued in healthcare, not only by nurses but also by clinicians in many other disciplines. Following the advent of EHRs [electronic health records], many nurses expressed dismay at the loss of space in the patient record to write narratives, to tell a story about what is happening to the patient and what occurred in the course of care. Such narratives are considered to be essential for communication between members of the team of healthcare professionals taking care of the patient. Although some like their ease of use, many nurses feel that "check boxes" and menu items don't sufficiently capture this element of care, and that limited comment fields are inadequate. It's true that structured drop-down menus, a prominent feature of EHRs, are very different from paper records. But do such menus improve or detract from the quality of documentation and, by extension, the quality of patient care? Drop-down menus with a panoply of choices could aid nurses by not requiring them to rely on memory for what should be assessed and documented. On the other hand, picking items from a menu, rather than using critical thinking to determine what is important to a particular patient's care, could also impair the development of those higher-level skills. Furthermore, selecting only from a menu could limit the full description of the patient's clinical status. [http://www.medscape.com/viewarticle/810573\\_5](http://www.medscape.com/viewarticle/810573_5)

## Media Watch Online

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/1/media-watch/>

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

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

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

### **Asia**

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

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

### **Australia**

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

### **Canada**

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

ONTARIO | Central West Palliative Care Network: [http://cwpcn.ca/Health\\_Practitioners/resources.htm?mediawatch=1](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.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to 'Additional Resources']

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/news-events> [Scroll down to 'Media Watch']

### **Europe**

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

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

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

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