

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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The role of the institutional ethics committee: Scroll down to [Specialist Publications](#) and 'Dispute resolution mechanisms for intractable medical futility disputes' (p.11), in *New York Law School Law Review*.

Canada

Life's last milestone: Why a "good death" matters

THE GLOBE & MAIL | Online – 14 February 2014 – David McMaster was dying. What shocked his family was the way it happened. "We were robbed of the chance to say a proper goodbye," says his daughter Susan. Mr. McMaster, 80, had been in and out of Sunnybrook Health Sciences Centre in 2010 with a series of complex circulatory and kidney problems. Eventually he also contracted C difficile, a hospital based-infection. After a week in the Intensive Care Unit on a breathing machine, doctors decided nothing more could be done; it was time to move him to "comfort care." But the only available bed was on a general medicine ward with two other patients. So instead of a peaceful atmosphere, Mr. McMaster ended up in pain, gasping for breath in a tiny room noisy with boisterous visitors and clanging cell phones. Even worse, Mr. McMaster's daughter couldn't rouse a nurse or a doctor in the middle of the night – so she watched her father struggling "for a gruelling" 90 minutes before he was given appropriate sedation. He finally fell into a deep slumber, but Susan kept guard for the rest of the night and remained with her father until he died later that afternoon. "I wouldn't want this to happen to my mortal enemy," she says. Most people envisage soft music, gentle lights, and family and friends swaddling them in love as they are ushered from this world into whatever lies beyond, but the ghastly reality that the McMaster family experienced is far too common. Instead of stewing over her father's death, though, Susan McMaster decided to be proactive and present her case to the hospital. Her complaints challenged Sunnybrook to rethink end of life care. They also speak to a much bigger challenge – to redefine what a "good death" looks like, both in and out of hospital, in time to support a rapidly aging population. And to reconsider our own responsibility for planning life's last big milestone. <http://www.theglobeandmail.com/life/health-and-fitness/health/the-hospital/lifes-last-milestone-why-a-good-death-matters/article16896444/>

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.15.

Pulling the plug: Doctors' perspective

ONTARIO | CBC ('White Coat, Black Art' blog) – 10 February 2014 – In 2010, Hassan Rasouli went into a coma following surgery to remove a brain tumour. He's been on a ventilator ever since. His doctors wanted to pull the plug, but the family refused permission. Last October, the Supreme Court of Canada sided with the family. A commentary in the *Canadian Medical Association Journal* [see sidebar next column] says the Court's decision makes it harder for doctors to take care of patients at the brink. Mr. Rasouli has been dependent on a ventilator and tube feedings since being in coma. His doctors wanted to discontinue life support after they deemed him to be in a persistent vegetative state without hope of improvement. They felt that the ventilator was only intended to support him until he recovered. Given no hope of recovery, they believed that the ventilator was no longer medically indicated and could – according to the law – be withdrawn without the approval of Mr. Rasouli's family. The family believes that Mr. Rasouli has shown

improvements, is aware of his surroundings and that he can communicate. Arguing that the doctors had no right to pull the plug without the family's consent, Mr. Rasouli took the doctors to court and won. The doctors lost appeals both to the Ontario Court of Appeal and the Supreme Court. The Supreme Court decision does not mean that doctors must keep Mr. Rasouli on a ventilator for the rest of his life. For one thing, it's entirely possible that one day, the family will conclude keeping Mr. Rasouli on a ventilator is futile, and permit doctors to turn it off. <http://www.cbc.ca/whitecoat/blog/2014/02/10/pulling-the-plug-doctors-perspective/>

Specialist Publications

'Supreme Court of Canada ruling on life support has wider impact: Hassan Rasouli' (p.11), in *Medical Press*.

N.B. Response to the 'White Coat, Black Art' blog from the authors of the commentary published in the *Canadian Medical Association Journal* (posted on the website of the Ontario-focused Health-care Consent Quality Collaborative): <http://consentqi.ca/response-brian-goldman/>

Of related interest:

- BRITISH COLUMBIA | *The Globe & Mail* – 10 February 2014 – '**Margot Bentley case shows our health care system values its bureaucracy over its patients.**' Bentley was a long-time nurse, working mostly with patients with dementia. She was determined not to die a slow, lonely, frightful death like so many of her patients. So she planned ahead. Bentley wrote a living will, one that clearly stated that, when her time came, she did not want heroic measures taken to keep her alive. She also discussed the issue with her children, fully and openly, and they were in agreement. Bentley did everything right. Yet today, the 82-year-old, who is in the final stages of dementia, is being kept "alive" against her wishes and those of her family. And the B.C. Supreme Court says that's okay. How could this happen? When will the wishes of patients finally and rightfully take precedence over the paternalistic prurience of the medico-legal establishment? <http://www.theglobeandmail.com/life/health-and-fitness/health/margot-bentley-case-shows-our-health-care-system-values-its-bureaucracy-over-its-patients/article16774301/>



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>

Northern push for national end-of-life strategy

ONTARIO | *The Daily Press* (Timmins) – 9 February 2014 – The growing segment of seniors and higher mortality rates in the Northeast has fuelled a pressing need for palliative care in this region. "The Northeast has one of the fastest growing ageing population," said Andre Paradis, president of Horizons-Timmins Palliative Care. "Seniors account for 17.4% of the total population in the Northeast whereas the provincial average is 13.9%." Citing a study by the Northeast Ontario End of Life Network, Paradis said, "The number of people over the age of 65 (in this region) is expected to increase by 39% by 2016. We have a higher rate than average in morbidity and mortality with reduced years of life for various types of cancer, respiratory illnesses, cardiovascular diseases, accidents and suicides. For example, cardiovascular diseases is the single leading cause of mortality in Northern Ontario with a 50% higher prevalence of that than in urban areas of Ontario." <http://www.timminspress.com/2014/02/09/northern-push-for-national-end-of-life-strategy>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *The Epoch Times* – 12 February 2014 – **"Father of palliative care" slams Quebec euthanasia bill.** Dr. Balfour Mount has made it his life's work to help ease the suffering of critically ill patients. He coined the phrase "palliative care" (to palliate means to improve the quality of something), and set up the first ward at McGill's Royal Victoria Hospital in 1973. Mount, 74, has a unique perspective on the euthanasia debate, having experience on both sides of the hospital bed. He has survived decades of critical illness including testicular cancer in his 20s, esophageal cancer in his 60s, and a heart attack. Mount admits that in his darkest moments of suffering it was easy to lose hope and the will to live. Even now, he has to sleep sitting up because if he lies down the contents of his bowels will run into his lungs, and it's been that way for 14 years. Despite it all, he says euthanasia was never an option. http://www.theepochtimes.com/n3/504138-father-of-palliative-care-slams-quebec-euthanasia-bill/#?photo=2&_suid=13923055052680965196404194543

U.S.A.

House panel votes on bill that would allow terminally ill patients to receive non-FDA approved drugs

ARIZONA | *The East Valley Tribune* (Tempe) – 14 February 2014 – Saying some chance is better than none, a House panel voted to let terminally ill patients get drugs that have not yet been approved for use. The 5-3 vote by the House Committee on Reform & Human Services came after testimony from Steven Walker about the cancer death of his wife, Jennifer McNeillie more than a decade ago. Walker, co-founder of the Abigail Alliance for Better Access to Developmental Drugs, said she was denied access to drugs then considered experimental but since approved by the U.S. Food & Drug Administration [FDA]. "The FDA was much more focused on statistical minutiae," he told lawmakers. "They were more focused on the process than delivery." The vote is just the first step in the process. Aside from still needing full House and Senate approval, it is crafted to give voters the last word: The measure would be placed on the November ballot. http://www.eastvalleytribune.com/arizona/capitol_media_services/article_ed81d102-94ed-11e3-b08f-0019bb2963f4.html

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>

Who wants to die? Not me – but can we at least talk about it?

MASSACHUSETTS | WBUR Radio (Boston) – 14 February 2014 – Let me be absolutely clear: I have no interest in dying. I love life. When my time is up and I must die, I imagine I'll react like everyone else: I will not want to depart, and I will be frightened. But, unless death surprises me and snaps me up like a frog snagging a fly, I want the freedom to choose how and when I go. Living wills and overly regulated assisted-suicide laws miss the point. I imagine only a brief window of lucidity between the freedom to act and the prison to which some incapacitating disease consigns me, making my exit so much more difficult and protracted. I'd prefer a gentle, painless fade to black over a lingering agony, especially when that agony is likely also to devour the people I love and drain the funds that should go to support my wife. When I try to discuss this sort of alter-

native, people become annoyed or angry. They say that this option is selfish, inconsiderate of the feelings and needs of those left behind. It seems that the grief generated even by the thought of death prevents us from considering the feelings and needs of the dying. We grieve mostly for an image of ourselves bereft of the one we love; we grieve for our loneliness, our loss. <http://cognoscenti.wbur.org/2014/02/13/death-with-dignity-alden-s-blodget>

Specialist Publications

'A new model for end-of-life care in nursing homes' (p.9), in *Journal of the American Medical Directors Association*.

Case of Marlise Muñoz serves as launchpad for future rulings

TEXAS | *The Daily Cougar* (University of Houston) – 12 February 2014 – Some of the Republican candidates running for Texas lieutenant governor have even stated Judge Wallace was wrong [in the case of Marlise Muñoz] to have let Muñoz be taken off life support and promised to, if elected, "tighten state law" to not let something like this happen again. But is it prudent to make a fixed ruling in such matters – to tie the hands of hospitals and families? In the background description of the Advance Directives Act, the Texas Hospital Association said, "the state's Advance Directives Act attempts to balance the rights of patients and providers and relies on medical knowledge and judgment to make appropriate treatment decisions based on the patient's condition." Each case is different, so to use a strict cookie-cutter rule would be pointless. That is why the state has made a law that allows people to make a choice and provides guidelines for them to follow to help make the best choice. It is hard to make a decision regarding the life of a loved one, and it can cause a lot of stress for the family. Unfortunately, in Muñoz's case, she and her baby could not be saved, but that doesn't mean all similar cases will end the same way. In the end, it all depends on what is best for that family at that time. <http://thedailycougar.com/2014/02/12/case-marlise-munoz-serves-launchpad-future-rulings/>

Focus on family-caregiver discrimination growing

HUMAN RESOURCE EXECUTIVE | Online – 10 February 2014 – With aging baby boomers still lingering in the workplace, a growing number of them caring for elderly and ailing parents, and with the federal government – namely the U.S. Equal Opportunity Commission – continuing to step up policing efforts against family and caregiver responsibility discrimination, attention to this segment of employment law is intensifying. Latest figures from The Center for WorkLife Law at the University of California Hastings College of the Law in San Francisco show more than 40 million people, about one in every eight Americans, are age 65 and older, and this number is projected to grow to an estimated 72 million, or one in five Americans, by 2030. The Center's latest poll information also shows more than 35% of employees have elder-care responsibilities and one in 10 employees have caregiving responsibilities for both children and elderly relatives. <http://www.hreonline.com/HRE/view/story.jhtml?id=534356659>

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Of related interest:

- **FORBES** | Online – 10 February 2014 – **'The family leave law is failing family caregivers.'** The Family & Medical Leave Act [1993] ... is failing for many working Americans in their 50s and 60s who need time off to care for their parents, spouses or partners. The law ... has an admirable goal: guaranteeing up to 12 weeks of unpaid leave to workers recovering from a serious medical condition and those caring for seriously ill spouses, parents or children or for new children. The Act ... also generally guarantees your job – unless you're among the highest-paid 10% of employees where you work. 40% of the workforce isn't covered by the law. <http://www.forbes.com/sites/nextavenue/2014/02/10/the-family-leave-law-is-failing-family-caregivers/>

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.¹ <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

Program puts monkeys in classrooms to help certain students

MISSOURI | Channel 5 News (St. Louis) – 10 February 2014 – With the diagnosis of a serious or terminal illness comes time away from school. Whether it is only a day here and there, or maybe weeks or months at a time, there is a program that helps everyone involved. The 'Monkey in My Chair' program was originally developed for preschool and elementary aged children who are away from school because of a cancer diagnosis. Each child is provided with a "monkey kit," which includes a big stuffed monkey that takes their place in school when they are unable to be there. The kit also includes the monkey with a backpack, a book to help teachers explain to students the situation their classmate is facing, and how it affects them, teacher companion guide, along with other items that can be utilized by the child and/or their classmates. All kits are sent out at no cost to the families or hospitals. In addition to each "monkey kit," each child is given online access to 'Monkey Message' ... that allows the sharing of pictures and documents to ensure the line of communication stays open between the patient and the classroom. <http://www.ksdk.com/story/entertainment/television/today-in-st-louis/2014/02/10/program-puts-monkeys-in-classrooms-to-help-certain-students/5357585/>

Hospice moving into hospitals to aid frail patients

OHIO | *The Columbus Dispatcher* – 10 February 2014 – As Sue Myers absorbed the news her husband, Leonard, was nearing the end of his life, her instinct was to bring him home to die. Len, as she called him, had been treated at Ohio State University's Wexner Medical Center for heart disease and other health problems, but medical interventions no longer promised improvement or cure for the 75-year-old Middletown man. The trouble was he was too frail for a trip home. The Ross Heart Hospital offered an alternative. He could move to a hospice room on the sixth floor, a place dedicated to managing pain and optimizing comfort. The couple said yes in mid-November, making Mr. Myers the first patient admitted to one of two hospice rooms that Wexner Heritage Village's Zusman Hospice began to operate that month. The partnership is part of broader plans to improve post-hospital care. <http://www.dispatch.com/content/stories/local/2014/02/10/hospice-moving-in-to-aid-frail-patients.html>

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Noted in Media Watch, 27 January 2014, #342 (p.3):

- ALABAMA | *UAB News* (University of Alabama at Birmingham) – 21 January 2014 – '**Hospice techniques for hospitalized patients provide better end-of-life care.**' Researchers at the Birmingham Veterans Affairs Medical Center and the University of Alabama at Birmingham say using home-based hospice practices for terminally ill, hospitalized patients could reduce suffering and also improve end-of-life care. <http://www.uab.edu/news/latest/item/4054-va/uab-study-hospice-techniques-for-hospitalized-patients-provide-better-end-of-life-care>

International

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

Funding gap is leaving children waiting for help

U.K. (England) | *The Birmingham Post* – 14 February 2014 – A baby hospice set up to care for severely sick children is being forced to reduce its opening hours and close off vital rooms due to a funding shortage. The centre cares for children from birth to the age of five, has five full-time nurses and four support workers, but that is not enough. The hospice runs on a monthly timetable and the number of staff available from week to week determines how many days the centre can open. Currently it's never more than four. There are 20 children on the books but the hospice can manage just four at a time, so children have to wait

their turn. Zoe's Place is entirely dependent on public donations and applying for grants. <http://www.birminghampost.co.uk/news/health-news/coventry-baby-hospice-suffering-funding-6695693>

Specialist Publications

'**Social support for South Asian Muslim parents with life-limiting illness living in Scotland: A multi-perspective qualitative study**' (p.8), in *BMJ Open*.

End-of-life care in Australia

Knowledge lacking on end-of-life rights

AUSTRALIAN AGEING AGENDA | Online – 12 February 2014 – The end-of-life wishes of people with dementia are not being met and this is partly due to a lack of knowledge among care professionals about a person's right to refuse treatments, according to a report by Alzheimer's Australia and Palliative Care Australia.¹ The survey found that one in five family carers (20%) and almost one in three culturally and linguistically diverse family carers (30%) were dissatisfied or very dissatisfied with the wishes of the person with dementia being followed. Almost a third of care professionals (31%) reported being unable to follow the end-of-life wishes of a person with dementia. <http://www.australianageingagenda.com.au/2014/02/12/knowledge-lacking-end-life-rights/>

1. *End-of-Life Care for People with Dementia: Executive Summary*, Alzheimer's Australia, February 2014. http://www.fightdementia.org.au/common/files/NAT/EOI_ExecSummary_Web_Version.pdf

Noted in Media Watch, 27 January 2014, #342 (p.4):

- *AUSTRALIAN AGEING AGENDA* | Online – 24 January 2014 – '**Doctors acknowledge education gap on end of life.**' The Royal Australian College of General Practitioners says it supports advance care planning becoming a routine part of general practice and has developed learning resources to help GPs, while the Australian Medical Association says it supported expanding the Practice Incentive Program to include advance care planning. <http://www.australianageingagenda.com.au/2014/01/24/doctors-acknowledge-education-gap-end-life/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BELGIUM | BBC News – 13 February 2014 – **'Belgium's parliament votes through child euthanasia.'** Parliament in Belgium has passed a bill allowing euthanasia for terminally ill children without any age limit, by 86 votes to 44, with 12 abstentions. When, as expected, the bill is signed by the king, Belgium will become the first country in the world to remove any age limit on the practice. It may be requested by terminally ill children who are in great pain and also have parental consent. Opponents argue children cannot make such a difficult decision. It is 12 years since Belgium legalised euthanasia for adults. <http://www.bbc.co.uk/news/world-europe-26181615>
- EUROPE | *Deutsche Welle* (Germany) – 13 February 2014 – **'Europe split on right-to-die regulations.'** Thus far, the European Union has kept its hands off the law books when it comes to a blanket regulation of right-to-die regulations in member states. *Deutsche Welle* takes a look at the varying attitudes amongst EU members. <http://www.dw.de/europe-split-on-right-to-die-regulations/a-17383707>
- FRANCE | Agence France-Presse – 13 February 2014 – **'Family battle over euthanasia for quadriplegic in French court.'** France's highest civil court began hearing the case of a battle between family members over ending the life of a 38-year-old quadriplegic in a vegetative state. The State Council's 17 judges started considering the case of Vincent Lambert. Doctors treating Lambert, as well as his wife, want to cut off intravenous food and water supplies but his deeply religious Catholic parents and other family members oppose the decision and took the matter to court. A court in Chalons-en-Champagne ruled against ending his life last month and the case was brought to the State Council on appeal. A 2005 law in France legalised passive euthanasia, where a person causes death by withholding or withdrawing treatment that is necessary to maintain life. <http://www.globalpost.com/dispatch/news/afp/140213/family-battle-over-euthanasia-quadruplegic-french-court-0>
- INDIA (Tamil Nadu) | *The Hindu* (Chennai) – 11 February 2014 – **'Supreme Court reserves verdict on voluntary passive euthanasia.'** Can a person afflicted with a terminal disease be allowed to refuse essential artificial medical support systems as he does not want to prolong his agony? The issue of voluntary passive euthanasia was debated extensively before the Supreme Court which has reserved its order on it. <http://www.thehindu.com/news/national/sc-reserves-verdict-on-voluntary-passive-euthanasia/article5677346.ece>

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

The study on evaluation and improvement of quality of life in patients with advanced cancer by China's Hospice Program

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 13 February 2014 – This multicenter study evaluated the quality of life (QOL) of patients with advanced cancer and assessed the improvement in patients' QOL by hospice service program, using McGill Quality of Life Questionnaire-Hong Kong version (MQOL-HK) questionnaire in China's 32 hospice centers from March to June, 2012. Compared to pre-hospice results, patients' QOL scores improved significantly in physical, psychological, existential, and support domains after three weeks of hospice services. The MQOL-HK questionnaire could effectively measure QOL in Chinese hospice patients and their QOL could be improved by hospice services. Psychological, existential, and support services should be emphasized during patients' initial three weeks of hospice admission. <http://ajh.sagepub.com/content/early/2014/02/12/1049909114523331.abstract>

Public preferences and priorities for end-of-life care in Kenya: A population-based street survey

BMC PALLIATIVE CARE | Online – 15 February 2014 – This first population-based survey on preferences and priorities for end-of-life care in Africa revealed that psycho-social domains were of greatest importance to the public, but also identified variations that require further exploration. The development of end-of-life care services to deliver preferences in Kenya should ensure an holistic model of palliative care responsive to individual preferences across care settings including at home. <http://www.biomedcentral.com/content/pdf/1472-684X-13-4.pdf>

Social support for South Asian Muslim parents with life-limiting illness living in Scotland: A multi-perspective qualitative study

BMJ OPEN | Online – 6 February 2014 – South-Asian parents at the end of life had limited access to extended-network support. Gender roles appeared as challenging for healthcare providers who at times overestimated the amount of support a female carer could provide and underestimated the amount of support male carers provided. Implications for practice include the need for greater awareness by healthcare providers of the social support needs of ethnic minority and migrant parents with life-limiting illnesses and especially an awareness of the importance of the role of male and female carers. <http://bmjopen.bmj.com/content/4/2/e004252.abstract>

Should we involve terminally ill patients in teaching medical students? A systematic review of patient's views

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 12 February 2014 –Understanding the patient's perspective provides a number of practical points in relation to how clinical teaching should be adapted in this patient group; for example, using smaller student group sizes; direct supervision if physical examination performed; short encounters with multiple patients rather than a longer encounter with one patient; adequate informed consent beforehand and without the students automatically being present. <http://spcare.bmj.com/content/early/2014/02/12/bmjspcare-2013-000535.abstract>

Palliative social media

BMJ SUPPORTIVE & PALLIATIVE CARE, 2014;4(1):13-18. The uses of social media have become ubiquitous in contemporary society at an astonishingly fast-paced rate. The Internet and in particular platforms such as Facebook, Twitter and YouTube are now part of most people's vocabulary and are starting to replace many face-to-face interactions. The online world, in particular, is alive with discussions, comments and anecdotes about the topics of illness, disease, hospitals, death and dying. The topic of death and dying had in the not too distant past been seen as taboo, but willingness and need to talk openly about it appears to be on the increase. In parallel to this, many public awareness campaigns are highlighting society's need to be more prepared for dying and death. <http://spcare.bmj.com/content/4/1/13.abstract>

Representative sample of articles on social media and dying and death noted in past issues of Media Watch:

- *THE INFORMATION SOCIETY*, 2013;29(3):190-195. **'The digital remains: Social media and practices of online grief.'** This article analyzes comments posted in response to articles and blog posts discussing Facebook's policies on the pages of deceased site members. These virtual discourses reflect the socio-cultural importance of social media policies in everyday life that is increasingly a blend of online and offline interaction. [Noted in Media Watch, 13 May 2013, #305 (p.14)] <http://www.tandfonline.com/doi/abs/10.1080/01972243.2013.777311>

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- NATIONAL PUBLIC RADIO | Online – 28 March 2013 – **'Why more patients should blog about illness and death.'** Blogging empowers patients to talk about illness outside the typical frame of "the battle" ... and reading the stories helps family members, too. [Noted in Media Watch, 1 April 2013, #299 (p.3)] <http://www.npr.org/blogs/health/2013/03/26/175383540/why-more-patients-should-blog-about-illness-and-death>
- OMEGA – JOURNAL OF DEATH & DYING, 2012;64(4):275-302. **'Does the Internet change how we die and mourn?'** The article outlines issues the internet presents to death studies. Part 1 describes a range of online practices that may affect dying, the funeral, grief and memorialization, inheritance and archaeology. Part 2 argues these online practices have implications for ... key concepts in death studies. [Noted in Media Watch, 5 March 2012, #243 (p.11)] <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue.1.6;ournal.1.255;linkingpublicationresults.1:300329.1>

Implementing an advance care planning program in German nursing homes: Results of an inter-regionally controlled intervention trial

DEUTSCHES ÄRZTEBLATT INTERNATIONAL, 2014;111(4):50-57. The implementation of an advance care planning program in German nursing homes led, much more frequently than previously reported, to the creation of advance directives with potential relevance to medical decision-making. Future research should assess the effect of such programs on clinical and structural outcomes. <http://www.aerzteblatt.de/pdf.asp?id=152957>

A guide to determine the next palliative home care nurse visit

HOME HEALTHCARE NURSE, 2014;32(2):88-95. *The Palliative Care: Determining Next Home Care Nurse Visit* supports clinicians in their decision-making process of planning visits to most effectively meet the needs and goals of patients and families during the final months of life. http://journals.lww.com/homehealthcarenurseonline/Fulltext/2014/02000/Applying_Research_Into_Practice_A_Guide_to.4.aspx

A new model for end-of-life care in nursing homes

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 10 February 2014 – This study aimed to promote quality end-of-life (EOL) care for nursing home residents, through the establishment of advance care plan (ACP) and introduction of a new care pathway. This pathway by-passed the emergency room (ER) and acute medical wards by facilitating direct clinical admission to an extended-care facility. A total of 76 patients were hospitalized from January to March 2013 ... 30 (39%) were directly admitted to the extended-care facility, either through the liaison of Community Geriatrics Outreach Service or transferred from the ER. The remaining 46 patients were admitted via the ER to acute medical wards following the usual pathway, followed by transfer to an extended-care facility if indicated. The ACP compliance rate was nearly 100%. Nearly 40% of EOL patients could be managed entirely in an extended-care setting without compromising the quality of care and survival. A greater number of patients may benefit from the EOL program by improving the collaboration between community outreach services and ER... [http://www.jamda.com/article/S1525-8610\(13\)00661-0/abstract](http://www.jamda.com/article/S1525-8610(13)00661-0/abstract)

Noted in Media Watch, 11 November 2013, #331 (p.12):

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 7 November 2013 – **'Racial disparities in receipt of hospice services among nursing home residents.'** Compared to White nursing home residents, Black, Hispanic and Asian residents who received hospice services were significantly less likely overall to have documented advance directives. All racial groups were also more likely to experience hospitalization, regardless of whether they had a documented "do not hospitalize" order. As nursing homes become more diverse, recognizing differences in hospice use and end-of-life planning will continue to increase in importance. <http://ajh.sagepub.com/content/early/2013/11/07/1049909113511144.abstract>

Cont.

Noted in Media Watch, 29 April 2013, #303 (p.16):

- *PALLIATIVE MEDICINE* | Online – 23 April 2013 – 'Improving end-of-life care in nursing homes: Implementation and evaluation of an intervention to sustain quality of care.' While good support from palliative care nurse specialists and GPs can help ensure that key processes remain in place, stable management and key champions are vital to ensure that a palliative care approach becomes embedded within the culture of the care home. <http://pmj.sagepub.com/content/early/2013/04/19/0269216313480549.abstract>

Use of a patient preference predictor to help make medical decisions for incapacitated patients

JOURNAL OF MEDICINE & PHILOSOPHY | Online – 13 February 2014 – The standard approach to treatment decision making for incapacitated patients often fails to provide treatment consistent with the patient's preferences and values and places significant stress on surrogate decision makers. These shortcomings provide compelling reason to search for methods to improve current practice. Shared decision making between surrogates and clinicians has important advantages, but it does not provide a way to determine patients' treatment preferences. Hence, shared decision making leaves families with the stressful challenge of identifying the patient's preferred treatment option. This paper proposes to incorporate the use of a "patient preference predictor" (PPP) into the shared decision-making process between surrogates and clinicians. <http://jmp.oxfordjournals.org/content/early/2014/02/12/jmp.jhu001.abstract?sid=33063f86-0c8c-48c5-9b57-c56409d8ac66>

N.B. 'Predicting end-of-life treatment preferences: Perils and practicalities,' comment on the above article: <http://jmp.oxfordjournals.org/content/early/2014/02/12/jmp.jhu007.abstract?sid=33063f86-0c8c-48c5-9b57-c56409d8ac66>

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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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.

Supreme Court of Canada ruling on life support has wider impact: Hassan Rasouli

MEDICAL PRESS | Online – 10 February 2014 – In the debate over whether to withdraw life support for patients who have no hope of recovery, the recent judgment by the Supreme Court of Canada on the Hassan Rasouli case in Ontario has broader implications for health care in the country, argue authors in a commentary in the *Canadian Medical Association Journal*.¹ The Supreme Court of Canada ruled in October 2013 that physicians who recommend withdrawing life support over the wishes of substitute decision-makers must apply to Ontario's Consent & Capacity Board (OCCB), "regardless of whether they feel ongoing treatment falls within the medical standard of care." This ruling will most likely have implications across the country. "First, the ruling will likely affect standard of medical care and practice well beyond Ontario. Second, there are potentially substantial resource implications for Ontario now that the Supreme Court's decision has given the OCCB a lar-

ger role to play in end-of-life decision-making," writes Robert Sibbald, London Health Sciences Centre, and adjunct professor, Faculty of Medicine, Western University, London, Ontario, with co-authors. "OCCB is a quasijudicial tribunal that does not benefit from expertise in critical care medicine. Yet it is now the first line of legal adjudication in the province in one of the most complex fields of medicine," the authors write. "An interesting potential outcome is that if the OCCB determines that ongoing ventilation is in the best interests of the patient, then the Board will essentially have the power to mould a medical standard of care contrary to the professional opinion regarding benefit." The Consent & Capacity Board, although useful in some cases, should have no role in questioning the judgment of trained, experienced physicians about whether a medical treatment is beyond the standard of care. <http://medicalxpress.com/news/2014-02-supreme-court-canada-life-wider.html>

1. 'Standard of care and resource implications of the *Cuthbertson vs. Rasouli* ruling,' *Canadian Medical Association Journal*, 10 February 2014 (subscription required to access commentary): <http://www.cmaj.ca/content/early/2014/02/10/cmaj.131640.full.pdf+html?sid=1d32a190-82ce-4286-9484-8c2ba06b4ecd>

Of related interest:

- *MEDICAL DAILY* | Online – 10 February 2014 – '**Canada establishes "death panel" for specific end-of-life decisions.**' A Canadian Supreme Court ruling establishes for specific end-of-life medical decisions what American conservatives refer to derisively as a "death panel." <http://www.medicaldaily.com/canada-establishes-death-panel-specific-end-of-life-decisions-269000>

Dispute resolution mechanisms for intractable medical futility disputes

NEW YORK LAW SCHOOL LAW REVIEW, 2013-2014;58(2):347-368. Many hospital policies give a central decision making role to the institutional ethics committee. Specifically, these policies give the ethics committee not only a role to mediate, but also a role to adjudicate futility disputes. The traditional hospital ethics committee is not up to this adjudicatory task. It lacks the necessary independence, diversity, composition, training or resources. Ethics committees are overwhelmingly intramural bodies, comprised of professionals employed directly or indirectly by the very same institution whose decisions the ethics committee adjudicates. In short, ethics committees can make decisions that are corrupted, biased, careless, and arbitrary. Reconstituting intramural ethics committees as multi-institutional committees can significantly mitigate these risks. They are detached from what is often the unduly persuasive influence of individual supporting institutions. Consequently, the multi-institutional ethics committee can operate as a diverse, accountable and independent decision making body that can ensure difficult bioethical dilemmas are addressed with enhanced uniformity and care. http://www.nylslawreview.com/wordpress/wp-content/uploads/2014/01/NYLS_Law_Review.Volume-58_Issue-2_Pope-article.pdf

Cont.

Noted in Media Watch, 11 November 2013, #331 (p.7):

- *CHEST*, 2013;144(5):1707-1711. **'Medical futility procedures: What more do we need to know?'** Unilateral medical futility policies, which allow health-care providers to limit or withdraw life-sustaining treatment over patient or surrogate objections, are increasingly designed around a procedural approach. Medical or ethics committees follow a pre-specified process, the culmination of which is a justified decision about whether ongoing treatment should be withheld or withdrawn.. <http://journal.publications.chestnet.org/article.aspx?articleid=1761255>

The challenges faced when leaving a children's hospice

NURSING CHILDREN & YOUNG PEOPLE, 2014;26(1):8-9. The move into adult services can leave young people with life-shortening conditions in Scotland facing an uncertain future, as they leave the comfort of children's services behind. Children's Hospice Association Scotland (CHAS), the charity that runs the country's two children's hospices, Rachel House and Robin House, and CHAS at Home, has introduced a policy to assist young people during this transition. The aim is to empower them to find age-appropriate services outside of CHAS by the age of 21. "Since CHAS first started 21 years ago we've seen an increasing number of young people living into adult life, when previously they may not have been expected to," says family support manager Arlene Honeyman. "This wonderful result, thanks to medical advances, has had an effect on CHAS, as we have increasingly seen that the services we provide at our two hospices are less appropriate for young adults. <http://rcnpublishing.com/doi/pdfplus/10.7748/ncyp2014.02.26.1.8.s9>

Noted in Media Watch, 13 May 2013, #305 (p.6):

- U.K. (SCOTLAND) | *The Herald* (Edinburgh) – 10 May 2013 – **'Hospice charity sets age limit on services for young people.'** While it does not usually work with young people of 16 or above, Children's Hospice Association Scotland has never had an age limit on how long existing users can carry on going to its hospices. However, children suffering from conditions such as muscular dystrophy, who were not expected to live past their teens when diagnosed, are often living into their 20s and 30s. <http://www.heraldsotland.com/news/health/hospice-charity-sets-age-limit-on-services-for-young-people.21041823>

Representative sample of articles on the transition to adult services for young people living with a terminal illness noted in past issues of Media Watch:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 December 2013 – **'Palliative care answers the challenges of transitioning serious illness of childhood to adult medicine.'** There is an urgent need to develop approaches that assist with the transition of care from pediatrics to adult medicine. [Noted in Media Watch, 6 January 2014, #339 (p.12)] <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0263>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 November 2013 – **'Young adult palliative care: Challenges and opportunities.'** From the data, two primary themes emerged 1) ongoing young adult development not only generates unique disease burdens and clinical treatment options, but also requires frequent assessment and promotion; and, 2) binary health care systems often leave young adults without access to developmentally appropriate health care. [Noted in Media Watch, 11 November 2013, #331 (p.6)] <http://ajh.sagepub.com/content/early/2013/11/06/1049909113510394.abstract>
- *PALLIATIVE MEDICINE* | Online – 18 October 2013 – **'Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: A qualitative study.'** Transition to adult services and adulthood is a prospect for young people with life-limiting conditions requiring palliative care. Transition planning [among the study participants] was absent or poorly coordinated; for most families, there were no equivalent adult health/social services. [Noted in Media Watch, 21 October 2013, #328 (p.13)] <http://pmj.sagepub.com/content/early/2013/10/15/0269216313507626.abstract>

Palliative care shortens ICU, hospital stays, review data show

THE ONCOLOGY TIMES | Online – 12 February 2014 – Palliative care in the intensive care unit reduces the length of stay in the ICU and the hospital without changing mortality rates or family satisfaction, according to a review of the literature. Although measurements of family satisfaction overall didn't change much from palliative care of a loved one in the ICU, some measures of components of satisfaction increased with palliative care, such as improved communication with the physician, better consensus around the goals of care, and decreased anxiety and depression in family members, reported Dr. Rebecca A. Aslakson of Johns Hopkins University, Baltimore. The review grouped results under four outcomes that commonly were measured, and assessed those either by the number of studies or by the number of patients studied. ICU length of stay decreased with palliative care in 13 of 21 studies (62%) that used this outcome and in 59% of 9,368 patients in those studies. Hospital length of stay decreased with palliative care in 8 of 14 studies (57%) and in 43% of 5,817 patients. Family satisfaction did not decrease in any studies or families and increased in only 1 of 14 studies (7%) and in 2% of families of 4,927 patients. <http://www.oncologypractice.com/oncologyreport/news/top-news/single-view/palliative-care-shortens-icu-hospital-stays-review-data-show/3c161a3e6d184048e4b91a5e0001394b.html>

Representative sample of articles on palliative care in ICU noted in past issues of Media Watch:

- *AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE* | Online – 21 November 2013 – **'Estimates of the need for palliative care consultation across U.S. ICUs using a trigger-based model.'** [In this study] approximately one in seven ICU admissions met triggers for palliative care consultation using a single set of triggers, with an upper estimate of one in five patients using multiple sets of triggers; these estimates were consistent across different types of ICUs and individual units. Results may inform staffing requirements for providers to ensure delivery of palliative care to ICU patients nationally. [Noted in Media Watch, 25 November 2013, #333 (p.7)] <http://www.atsjournals.org/doi/abs/10.1164/rccm.201307-1229OC>
- *CHEST* | Online – 10 October 2013 – **'Differences in end-of-life care in the ICU across patients cared for by medicine, surgery, neurology and neurosurgery physicians.'** Some of the challenges in the delivery of high quality end-of-life care in the ICU include the variability in the characteristics of patients with certain illnesses and the practice of critical care by different specialties. The findings of this study may provide insights into potential ways to improve the quality of dying for all patients. [Noted in Media Watch, 14 October 2013, #327 (p.8)] <http://journal.publications.chestnet.org/article.aspx?articleid=1750233>
- *JAMA INTERNAL MEDICINE* | Online – 9 September 2013 – **'The frequency and cost of treatment perceived to be futile in critical care.'** A survey of ICU physicians in Canada found that as many as 87% believed that futile treatment had been provided in their ICU in the past year. In a single-day cross-sectional study performed in Europe, 27% of ICU clinicians believed that they provided "inappropriate" care to at least one patient, and most of the inappropriate care was deemed such because it was excessive. In the U.S., critical care accounts for 20% of all health costs... Because approximately 20% of deaths in the U.S. occur during or shortly after a stay in the ICU, critical care is scrutinized for the provision of potentially futile resource-intensive treatment. [Noted in Media Watch, 16 September 2013, #323 (p.12)] <http://archinte.jamanetwork.com/article.aspx?articleid=1735897&resultClick=3>

Quotable Quotes

How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving and tolerant of the weak and strong. Because someday in your life you will have been all of these. George Washington Carver (1864-1943)

Grief functions as an honest indicator of commitment

PERSONALITY & SOCIAL PSYCHOLOGY REVIEW | Online – 5 February 2014 – Grief is a puzzling phenomenon. It is often costly and prolonged, potentially increasing mortality rates, drug abuse, withdrawal from social life, and susceptibility to illness. These costs cannot be repaid by the deceased and therefore might appear wasted. The authors propose a possible solution. Using the principles of social selection theory, they argue that an important selective pressure behind the human grief response was the social decisions of other humans. They combine this with insights from signaling theory, noting that grief shares many properties with other hard-to-fake social signals. <http://psr.sagepub.com/content/early/2014/02/05/1088868314521016.abstract>

Hope, positive illusions and palliative rehabilitation

PROGRESS IN PALLIATIVE CARE | Online – Accessed 12 February 2014 – In ordinary usage, the word "hope" is clear and unambiguous. But in the palliative care context it has been amplified, dramatized, glamorized, and spiritualized to the extent that it is no more than a piece of inflated rhetoric. In this paper, the author offers a simple analysis of a simple word; explains why the inflated sense is unhelpful; shows why hope does not have a straightforward "opposite"; and, argues that "hope" is not a name for a metaphysical, psychological, or spiritual something-or-other. However, bewitched by their inflated understanding of "hope," some palliative care professionals apparently tell patients and carers what they should hope for – which could hardly be more patronizing – while others use it as a portmanteau term to describe whatever positive health care outcomes take their fancy. The author's suggestion is that palliative rehabilitation specialists should resist the temptations of inflation and glamorisation, and begin to use the word more precisely, modestly, and transparently. There is no such thing as "hope" the life force, "hope" the inner power, "hope" the universal human phenomenon, or "hope" the theological virtue. <http://www.maneyonline.com/doi/abs/10.1179/1743291X14Y.0000000084>

Variation in do-not-resuscitate orders for patients with ischemic stroke: Implications for national hospital comparisons

STROKE | Online – 12 February 2014 – Decisions on life-sustaining treatments and use of do-not-resuscitate (DNR) orders can affect early mortality after stroke. The authors investigated the variation in early DNR use after stroke among hospitals in California and the effect of this variation on mortality-based hospital classifications. Failure to adjust for DNR orders resulted in substantial hospital reclassification across the rank spectrum, including among high mortality hospitals. There is wide variation in the hospital-level proportion of ischemic stroke patients with early DNR orders. Unless the circumstances of early DNR orders are better understood, mortality-based hospital comparisons may not reliably identify hospitals providing a lower quality of care. <https://stroke.ahajournals.org/content/early/2014/02/12/STROKEAHA.113.004573.abstract>

Noted in Media Watch, 30 September 2013, #325 (p.11):

- *EMERGENCY MEDICINE JOURNAL* | Online – 23 September 2013 – **'What do hospital mortality rates tell us about quality of care?'** Hospital mortality rates could be useful indicators of quality of care, but careful statistical analysis is required to avoid erroneously attributing variation in mortality to differences in health care when it is actually due to differences in case mix. <http://emj.bmj.com/content/early/2013/09/23/emered-2013-203022.abstract>

Noted in Media Watch, 8 November 2010, #174 (p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 November 2010 – **'Hospital mortality rates: How is palliative care taken into account?'** Using mortality rates to measure hospital quality presumes hospital deaths are medical failures. Palliative care and hospice leaders need to educate themselves and hospital administrators about the extent to which mortality rates take end-of-life care into account. [http://www.jpsmjournal.com/article/S0885-3924\(10\)00654-8/abstract](http://www.jpsmjournal.com/article/S0885-3924(10)00654-8/abstract)

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *HEALTH CARE*, 2014;2(1):10-14. **'State of palliative care development in European countries with and without legally regulated physician-assisted dying.'** The hypothesis that legal regulation of physician-assisted dying stunts the development of palliative care is not supported by the Belgian and Dutch experience of the first several years. Continued monitoring of both permissive and non-permissive countries is needed to assess possible longer-term effects. http://manuscript.sciknow.org/uploads/hc/pub/hc_1387399163.pdf

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/2/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 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

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']

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>

Worth Repeating

End-of-life care and the effects of bereavement on family caregivers of persons with dementia

NEW ENGLAND JOURNAL OF MEDICINE, 2003(20);349:1936-1942. Half the caregivers reported spending at least 46 hours per week assisting patients with activities of daily living and instrumental activities of daily living. More than half the caregivers reported they felt they were "on duty" 24 hours a day, that the patient had frequent pain, and that they had had to end or reduce employment owing to the demands of caregiving. Caregivers exhibited high levels of depressive symptoms while providing care to the relative with dementia, but they showed remarkable resilience after the death. Within three months of the death, caregivers had clinically significant declines in the level of depressive symptoms, and within one year the levels of symptoms were substantially lower than levels reported while they were acting as caregivers. Seventy-two percent of caregivers reported that the death was a relief to them, and more than 90% reported belief that it was a relief to the patient. <http://www.nejm.org/doi/full/10.1056/NEJMsa035373#t=article>

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