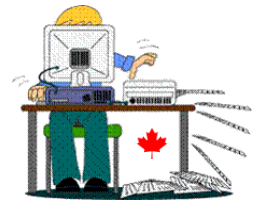


Media Watch...

is intended as an advocacy, research and teaching 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

The illness experience: Scroll down to [Specialist Publications](#) and 'Association between quality of end-of-life care and possible complicated grief among bereaved family members' (p.9), in *Journal of Palliative Medicine*.

Canada

For the dying: Health Sciences North eyeing Thunder Bay model for life support

ONTARIO | *Northern Life* (Sudbury) – 23 July 2014 – Representatives with Health Sciences North [HSN] plan to keep a close watch on a new policy in Thunder Bay that codifies decisions around life-sustaining treatment for patients. The Thunder Bay Regional Health Sciences Centre introduced new code status levels ... that identify the level of life support critically ill patients wish to receive. At level five, a patient would receive all medically appropriate life-sustaining measures. At level one, a patient wants only pain relief and palliative care to provide relief for any discomfort they may have. Levels two to four represent various levels of care in between the two extremes. Level three, for example, reads: "I do not want CPR. I will accept a medically appropriate trial of non-invasive ventilation, including life support." Patients wear different coloured armbands depending on which code status level they have chosen. HSN has had a level of treatment policy in place since 2003 that outlines how health-care professionals approach patients about their end-of-life care needs.

Several years ago, hospital staff discussed introducing armbands, as has been done in Thunder Bay, but decided against the idea. <http://www.northernlife.ca/news/localNews/2014/07/23-hsn-end-of-life-care-sudbury.aspx>

Extract from *Northern Life* article

[Hospital] staff determined the armbands [to identify code status] could infringe on patients' privacy by publicly disclosing their treatment wishes. They also felt the armbands could be problematic because it is not unusual for patients to change their minds about the level of life support they would like to receive.

Specialist Publications

'College of Physicians & Surgeons of Ontario poll reveals Canadians support doctors' moral right to deny treatment' (p.10), in *The Medical Post*.

U.S.A.

Uniform Fiduciary Access to Digital Assets Act

A plan to untangle our digital lives after we're gone

NATIONAL PUBLIC RADIO | Online – 23 July 2014 – As we live more and more of our lives online, more and more of what used to be tangible turns digital. "Where you used to have a shoebox full of family photos, now those photos are often posted to a website," notes Ben Orzeske, legislative counsel at the ULC. That shoebox used to go to the executor of the deceased's will, who would open it and distribute its contents to family members. The will's author could decide what she wanted to give and to whom. The Uniform Fiduciary Access to Digital Assets Act aims to make the digital shoebox equally accessible. "This is the concept of 'media neutrality,'" Orzeske explained. The law gives the executor of your estate access to digital assets in the same way he had access to your tangible assets in the old world. It doesn't matter if they're on paper or on a website." It turns out those terms-of-service agreements Internet users usually click through without reading include some strict rules: The small print on sites like Facebook and Google specifies that the user alone can access his or her account. But proposed law would override those contracts. The law's proponents say this change would solve a host of problems. For one thing, it would allow the executor and family members to clear up any unresolved financial matters in the wake of a death. <http://www.npr.org/blogs/alltechconsidered/2014/07/23/334051789/a-plan-to-untangle-our-digital-lives-after-were-gone>

Noted in Media Watch, 12 May 2014, #357 (p.4):

- IRELAND | *The Irish Examiner* (Blackpool, Cork) – 7 May 2014 – **'So much of our lives are online, but what happens when we die?'** So much of our lives are now played out online, but what happens after we die? We leave a digital legacy. A technological interface to provide comfort to our friends and relatives, in the form of our pictures, music, emails and thoughts via Twitter, Apple, Gmail, Microsoft and Facebook. But unlike the assets of our estate, dealt with by an executor of a will, our online activities have no actual value and therefore do not form part of a traditional will. We interact online having agreed to the terms and conditions of individual applications and websites. Therefore, any arrangements we choose to make for our digital legacy become a more complicated affair. <http://www.irishexaminer.com/technology/so-much-of-our-lives-are-online-but-what-happens-when-we-die-267669.html>

Advocates call on lawmakers to expand palliative care

WASHINGTON DC | *The Hill* – 23 July 2014 – Advocates are urging lawmakers to back pieces of legislation that would expand and improve palliative care... More than three dozen caregivers, patients and advocates for people with serious illness held meetings on Capitol Hill about two bipartisan proposals on pain medicine. One bill, from Senator Ron Wyden (Democrat-Oregon), would increase the number of pain professionals through grants, contracts and education centers aimed at raising the profile of palliative care. The other, from Representative Emanuel Cleaver (Democrat-Missouri), would encourage the development of best practices for the field and order federal research. Advocates affiliated with the Patient Quality of Life Coalition were quick to note that both measures are bipartisan. Republicans and Democrats have been able to work together on small healthcare bills this term despite widespread gridlock and rising election-year conflicts. <http://thehill.com/policy/healthcare/213102-advocates-call-on-lawmakers-to-expand-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.14.

Taking care of our caretakers

NATIONAL LAW REVIEW | Online – 20 July 2014 – Every day across our nation, about 2 million people, including 73,000 in Illinois, go to work caring for people in their homes. Their work is demanding. It can be dirty. It can be physically exhausting and emotionally draining. But it can also be enormously satisfying. Most important, it allows our loved ones to live in their homes with dignity and independence, rather than in institutions. And yet, until recently, these home care workers could be paid less than the minimum wage for their work. A decades-old exemption in federal regulations allowed them to be included in the same category as babysitters. The U.S. Department of Labor last year issued new regulations to address that problem, which means home care workers can no longer be paid a sub-minimum wage for the critical, difficult work they do. Unfortunately, last month the U.S. Supreme Court decision in *Harris v. Quinn* made it harder for home care workers in Illinois to get decent wages and benefits.¹ Nine out of 10 home care workers are women – about half of them are women of color. An estimated 40% are on some form of public assistance. They earn about \$20,000 a year, often working far more than 40 hours per

week. One woman told us she left her job as a home health aide to work at a fast food restaurant because it paid better. We can't afford to pay so little to workers who are in increasingly high demand. With our largest generation – baby boomers – hitting retirement age at a moment when American life expectancy is higher than ever, we'll need 50% more home care workers by 2022. <http://www.natlawreview.com/article/taking-care-our-caretakers>

Specialist Publications

'Geographic access to hospice care for children with cancer in Tennessee, 2009 to 2011' (p.9), in *American Journal of Hospice & Palliative Medicine*.

'From hospice to hospital: Short-term follow-up study of hospice patient outcomes in a U.S. acute care hospital surveillance system' (p.9), in *BMJ Open*.

'Financial hardship and the intensity of medical care received near death' (p.9), in *Psycho-Oncology*.

1. 'Supreme Court rules against union fees for some home care workers,' National Public Radio, 30 June 2014. The ruling is a setback for labor unions that have bolstered their ranks ... in Illinois and other states by signing up hundreds of thousands of in-home care workers. <http://www.npr.org/blogs/thetwo-way/2014/06/30/326926651/supreme-court-rules-against-union-dues-for-some-home-care-workers>

International

End-of-life care in Australia

Palliative care now has new ambulance options

AUSTRALIA (New South Wales – NSW) | *Narooma Today* – 23 July 2014 – Palliative care patients and their families in Narooma now have more options for end-of-life care, thanks to collaboration between NSW Ambulance and the region's largest health agencies. The Southern NSW Medicare Local and the Southern NSW Local Health District have joined forces with NSW Ambulance to promote a protocol that allows paramedics to treat palliative patients in their own home on the instructions of their GP rather than transfer them to hospital. Guidelines for GPs and a brochure for palliative care patients have now been distributed throughout southern NSW. <http://www.naroomanewsonline.com.au/story/2436222/palliative-care-now-has-new-ambulance-options/?cs=12>

Cont.

Noted in Media Watch, 31 March 2014, #351 (p.5):

- AUSTRALIA (New South Wales) | *The Braidwood Times* – 25 March 2014 – **'New options for palliative care.'** Southern NSW Medicare Local and Southern NSW Local Health District joined with NSW Ambulance to promote a protocol that allows paramedics to treat palliative patients in their own home on the instructions of their GP rather than transfer them to hospital. <http://www.braidwoodtimes.com.au/story/2174637/new-options-for-palliative-care/?cs=743>

[Singapore's] National Council of Social Service to develop framework for volunteer organisations

SINGAPORE | *Today* – 23 July 2014 – The National Council of Social Service will be developing a volunteer management framework for the social sector, as part of plans to beef up volunteer resources and develop the expertise of social service professionals. This could include a recognition system within voluntary welfare organisations (VWOs) to attract and retain quality volunteers and creating more development and training programmes. The Volunteer Resource Optimisation programme will redesign selected programmes and job processes ... and put in place systems for recruitment, training and deployment of volunteers. <http://www.todayonline.com/singapore/ncss-develop-framework-volunteer-organisations>

Specialist Publications

Specialisation in Palliative Medicine for Physicians in Europe 2014 (p.7), posted on the website of the European Association for Palliative Care.

'End-of-life care in high-grade glioma patients in three European countries: A comparative study' (p.8), in *Journal of Neuro-Oncology*.

'Improving inpatient hospice environments for older people in England: A documentary analysis' (p.13), in *Progress in Palliative Care*.

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

National Health Service "should work more closely with hospices"

U.K. (England) | BBC News – 23 July 2014 – Hospices could play a greater role in end-of-life care and stop hospitals being the "default option," says former Tory party leader Lord Howard. About half of people die in hospital – despite 80% preferring not to. Michael Howard, who is chairman of Help the Hospices, urged the NHS to work more closely with hospices to give people more choice at the end of life. The group is looking to set up a series of formal pilots in England later this year to see what could be achieved. The trials could involve hospice staff being placed in hospitals or providing more care in people's homes. There are examples of this already happening. For example, Watford General Hospital regularly has hospice staff on wards to help ensure those who want help from local hospices get it. Other areas are sending nurses into people's homes to provide end-of-life care, such as pain relief and emotional support. Help the Hospices believes extending such schemes could reduce the number of people dying in hospital by a 50,000 – a fifth. But the hospice movement says attempts to expand these schemes are hindered by a lack of money. About a third of their funding comes from the NHS with the rest relying on charitable donations. <http://www.bbc.com/news/health-28417560>

Of related interest:

- U.K. (Wales) | Marie Curie Cancer Care – Accessed 23 July 2014 – ***Dying at home: The role of social housing providers in supporting terminally ill people in Wales.*** This report has attempted to unpick some of the issues involved in supporting someone at the end of their life who lives in property owned by a housing association or local authority with a particular focus on extra care and sheltered housing. Many of the recommendations made here are not resource intensive. Instead, they involve greater communication, skills sharing and collaborative working across service sectors which ultimately have the wellbeing of the people they serve at their core. <http://www.mariecurie.org.uk/Global/Policy/Dying-at-home-report.pdf>

Home care in the U.K.

Our 30 care providers failing to meet national standards

U.K. (England) | *The Dorset Echo* (Weymouth) – 23 July 2014 – Thirty Dorset home care providers have failed to meet national standards for care, according to official reports from the Care Quality Commission (CQC). Of 14 home care providers for West Dorset which didn't meet all five CQC standards, over half – eight – failed to pass more than one standard. The Commission publishes its inspection reports online. Home care providers look after people who live independently in their own homes but require some help. The latest findings follow a *Dorset Echo* investigation into care homes in the county revealed shortcomings in the provision of care in the county. http://www.dorsetecho.co.uk/news/11358518.Our_30_care_providers_failing_to_meet_national_standards/?ref=var_0

N.B. The Care Quality Commission has drafted guidance on how the 46,000 health and adult social care providers and services that it regulates across England can meet the government's new regulations on care and what actions it will take when they fail. <http://www.cqc.org.uk/content/cqc-consults-how-providers-can-meet-new-fundamental-standards-care>

Of related interest:

- U.K. (Scotland) | *The Herald* (Edinburgh) – 15 July 2014 – **'Men who are carers can be left feeling isolated.'** A survey by the Carers' Trust Scotland (CTS)¹ ... claims well approaching one half (44%) of Scotland's unpaid carers are male, based on findings from the Scottish Health Survey. This means around 420,000 Scottish men and boys look after a friend or relative who is sick, disabled, frail or suffers from mental health or addiction problems. <http://www.heraldscotland.com/comment/columnists/inside-track-men-who-are-carers-can-be-left-feeling-isolated.24723600>

1. 'Husband, partner, dad, son, carer? A survey of the experiences and needs of male carers,' Carers' Trust Scotland, July 2014. http://www.carers.org/sites/default/files/male_carers_research.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- LITHUANIA | BioEdge – 26 July 2014 – **'Euthanasia could be option for poor, says Lithuanian health minister.'** Euthanasia might be needed for poor people who cannot access palliative care, the new Lithuanian Health Minister has suggested. Rimantė Šalaševičiūtė was sworn earlier this month, but already she has made waves by backing an open discussion of the legalisation of euthanasia. Without making any specific proposals, she told local media that Lithuania was not a welfare state with palliative care available for all and that euthanasia might be an option for people who did not want to torment relatives with the spectacle of their suffering. http://www.bioedge.org/index.php/bioethics/bioethics_article/11071



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>

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

The relationship between providing neonatal palliative care and nurses' moral distress: An integrative review

ADVANCES IN NEONATAL CARE | Online – 11 July 2014 – The purpose of this review was to determine the relationship between the provision of palliative care in a neonatal ICU and nurses' moral distress. The evidence reviewed supports that moral distress does occur with the provision of neonatal palliative care. An interdisciplinary care team, an established protocol, and educational interventions may decrease moral distress in nurses providing end-of-life care to infants... http://journals.lww.com/advancesinneonatalcare/Abstract/publishahead/The_Relationship_Between_Providing_Neonatal.99981.aspx

Noted in Media Watch, 3 December 2012, #282 (pp.13-14):

- *SEMINARS IN FETAL & NEONATAL MEDICINE* | Online – 22 November 2012 – '**Evidence-based comfort care for neonates towards the end of life.**' When examining the evidence-base for most interventions, it is lacking – but this is not unique to this aspect of neonatal care. Clinicians can acknowledge that patient needs require managing their end-of-life symptoms now; neither these patients nor their families should have to wait for research to catch up to their current needs. <http://www.sciencedirect.com/science/article/pii/S1744165X1200131X>

Whither brain death?

AMERICAN JOURNAL OF BIOETHICS, 2014;14(8):3-8. The publicity surrounding the recent McMath and Muñoz cases^{1,2} has rekindled public interest in brain death: the familiar term for human death determination by showing the irreversible cessation of clinical brain functions. The concept of brain death was developed decades ago to permit withdrawal of therapy in hopeless cases and to permit organ donation. It has become widely established medical practice, and laws permit it in all U.S. jurisdictions. Brain death has a biophilosophical justification as a standard for determining human death but remains poorly understood by the public and by health professionals. <http://www.tandfonline.com/doi/abs/10.1080/15265161.2014.925153?queryID=%24%7BresultBean.queryID%7D>

- '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>
- 'Case of Marlise Muñoz serves as launchpad for future rulings,' *The Daily Cougar* (Houston, Texas) – 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? [Noted in Media Watch, 17 February 2014, #345 (p.4)] <http://thedailycougar.com/2014/02/12/case-marlise-munoz-serves-launchpad-future-rulings/>

N.B. The focus of this issue of the *American Journal of Bioethics* is on brain death. Journal contents page: <http://www.tandfonline.com/toc/uajb20/current>

Of related interest:

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 24 July 2014 – '**East-west differences in perception of brain death.**' The concept of brain death as equivalent to cardiopulmonary death was initially conceived following developments in neuroscience, critical care, and transplant technology. It is now a routine part of medicine in Western countries, including the U.S. In contrast, Eastern countries have been reluctant to incorporate brain death into legislation and medical practice. <http://link.springer.com/article/10.1007/s11673-014-9564-x>

Specialisation in Palliative Medicine for Physicians in Europe 2014

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (EAPC) | Online – 21 July 2014 – A new report by the EAPC Task Force on the 'Process of Specialisation in Palliative Medicine in Europe' reveals that 18 out of 53 European countries have official specialisation programmes: the Czech Republic, Denmark, Finland, France, Georgia, Germany, Hungary, Ireland, Israel, Italy, Latvia, Malta, Norway, Poland, Portugal, Romania, Slovakia and the U.K. Ten of these programmes have been started in the last five years, demonstrating that palliative medicine is truly growing as a field of specialisation in Europe. <http://eapcnet.wordpress.com/2014/07/21/palliative-medicine-now-a-medical-specialty-in-18-european-countries/>

Medical futility in the era of evidence-based medicine

JOURNAL OF BIOMEDICAL RESEARCH | Online – 10 July 2014 – One definition of futility is any treatment that merely preserves permanent unconsciousness or fails to end total dependence of a patient on intensive medical care. However, no agreement has ever been reached on what the exact definition of futility is, as it is not only based on temporary values but also evolves into different subtypes, making it harder to define. The difficulty in dealing with futility is how doctors evaluate the futile situation, which is further complicated by lack of standards for specific diseases and experience-based prognosis, leading to subjectivity in evaluation for futility. Since judgment and decision making by physicians play an overwhelmingly dominant role in the estimation of futility, evidence-based medicine (EBM) should be included as a general guideline, incorporating individual experience and the best current evidence. EBM draws heavily from current research findings... Furthermore, this concept is evolving with the deepening and development of research, being an evolution itself. However, it is worthwhile to point out that EBM only predicts the effectiveness of an intervention by adjusting the earlier conclusion according to the newest results of research, but it cannot work in every particular case even in an approximation formula. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4102836/>

Extract from *Journal of Biomedical Research* article

Cardiopulmonary resuscitation (CPR) in the intensive care unit (ICU) is likely a futile exercise if indiscriminately practiced in patients, especially those who are unlikely to survive to hospital discharge. Despite the widespread use of do-not-resuscitate (DNR) orders, introduced nearly a half century ago, the outcome following CPR has not been substantially improved. Therefore, evidence-based selection of patients who will benefit from CPR is of paramount importance in avoiding medical futility. CPR is predicated on the assumption that CPR will be successful in maintaining the sacred life of a patient; to guard against its indiscriminate and sometimes excessive use, we should garner clinical evidence through clinical trials and development of prediction models and scoring systems such as the Good Outcome Following Attempted Resuscitation (GO-FAR) score to guide physicians in making informed decision on the use of CPR. On the other hand, the DNR order requires patient consent to prevent a medical procedure from being performed; many patients or surrogates may overestimate the effects of CPR and may oppose a DNR order by the physician.

Selected articles on medical futility noted in past issues of Media Watch:

- *NATIONAL CATHOLIC BIOETHICS QUARTERLY*, 2014;14(1):39-46. '**Clarifying the concept of medical futility.**' A futility judgment is clear cut when the procedure does not work, but a difficulty arises when a physician believes that a procedure provides too little benefit and then invokes futility. This article places the concept "medical futility" in relation to the principle of ordinary and extraordinary means... [Noted in Media Watch, 19 May 2014, #358 (p.7)] <http://ncbcenter.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,3,9;journal,1,53;linkingpublicationresults,1:119988,1>

Cont.

- *MAYO CLINICAL PROCEEDINGS* | Online – 10 April 2014 – '**Ten common questions (and their answers) on medical futility.**' This article introduces and answers ten common questions regarding medical futility in an effort to define, clarify, and explore the implications of the term. They discuss multiple domains related to futility, including the biological, ethical, legal, societal, and financial considerations that have a bearing on definitions and actions. [Noted in Media Watch, 14 April 2014, #353 (p.12)] [http://www.mayoclinicproceedings.org/article/S0025-6196\(14\)00163-3/abstract](http://www.mayoclinicproceedings.org/article/S0025-6196(14)00163-3/abstract)
- *NEW YORK LAW SCHOOL LAW REVIEW*, 2013-2014;58(2):347-368. '**Dispute resolution mechanisms for intractable medical futility disputes.**' Many hospital policies give a central decision making role to the institutional ethics committee. 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 independence, diversity, composition, training or resources. [Noted in Media Watch, 17 February 2014, #345 (p.11)] http://www.nylslawreview.com/wordpress/wp-content/uploads/2014/01/NYLS_Law_Review.Volume-58_Issue-2_Pope-article.pdf

End-of-life care in high-grade glioma patients in three European countries: A comparative study

JOURNAL OF NEURO-ONCOLOGY | Online – 20 July 2014 – Exploring cross-national differences is useful to evaluate whether different patterns of end-of-life (EOL) care meet patient's specific needs. This study aimed to 1) compare EOL care processes for high-grade glioma (HGG) patients in three European countries; 2) explore differences in perceived quality of care (QOC); and, 3) identify aspects of good QOC in the EOL phase. Three months before death 75 % of patients were at home. In all countries, on average, 50% were transferred to a hospital at least once and received effective symptom treatment during the last 3 months. In The Netherlands, Austria and the U.K., respectively, patients most often died at home (60%), in a hospital (41%) or hospice (41%)... Advance directives were present in 46% of Dutch, 36% of British and 6% of Austrian patients... Fifty-three percent of patients experienced good QOC, irrespective of country. Dying at the preferred place, satisfaction with information provided and effective symptom treatment were independently associated with good QOC. There are various cross-national differences in organization and experiences with EOL care for HGG, but patient's perceived QOC is similar in the three countries. As symptom treatment was considered effective in only half of HGG patients, and independently predicted good QOC, this particularly needs further improvement in all countries. <http://link.springer.com/article/10.1007/s11060-014-1548-5>

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

The quality imperative for palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 23 July 2014 – Palliative medicine must prioritize the routine assessment of the quality of clinical care we provide. This includes regular assessment, analysis, and reporting of data on quality. Assessment of quality informs opportunities for improvement and demonstrates to our peers and ourselves the value of our efforts. In fact, continuous messaging of the value of palliative care services is needed to sustain our discipline; this requires regularly evaluating the quality of our care. As the reimbursement mechanisms for health care in the U.S. shift from fee-for-service to fee-for-value models, palliative care will be expected to report robust data on quality of care. We must move beyond demonstrating to our constituents (including patients and referrers), "here is what we do," and increase the focus on "this is how well we do it" and "let's see how we can do it better." It is incumbent on palliative care professionals to lead these efforts. This involves developing standardized methods to collect data without adding additional burden, comparing and sharing our experiences to promote discipline-wide quality assessment and improvement initiatives, and demonstrating our intentions for quality improvement on the clinical frontline. [http://www.jpmsjournal.com/article/S0885-3924\(14\)00362-5/abstract](http://www.jpmsjournal.com/article/S0885-3924(14)00362-5/abstract)

Cont.

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 15 July 2014 – **'Geographic access to hospice care for children with cancer in Tennessee, 2009 to 2011.'** The geographic interface between the need for and the supply of pediatric hospice may be critical in whether children with cancer access care. This study sought to describe the geographic distribution of pediatric hospice need and supply, and identify areas lacking pediatric hospice care in Tennessee over a three-year time period. There was a consistent need for care among children with cancer across the state. Most urban areas were supplied by pediatric hospices, except the Knoxville area. Areas within the state were identified where the supply of pediatric hospice care declined, while the need for hospice care was unchanging. <http://ajh.sagepub.com/content/early/2014/07/14/1049909114543641.abstract>
- *BMJ OPEN* | Online – 22 July 2014 – **'From hospice to hospital: Short-term follow-up study of hospice patient outcomes in a U.S. acute care hospital surveillance system.'** There is little systematic evidence about the real-world trajectories of patient medical care after hospice enrolment. The objective of this study was to analyse predictors of the length of stay for hospice patients who were admitted to hospital in a retrospective analysis of the mandatorily reported hospital discharge data. [Results of this study] raise significant questions about the ethics and pragmatics of end-of-life medical care, and the intentions and scope of hospices in the U.S. <http://bmjopen.bmj.com/content/4/7/e005196.abstract>
- *PSYCHO-ONCOLOGY* | Online – 23 July 2014 – **'Financial hardship and the intensity of medical care received near death.'** Depletion of a family's financial resources is a significant predictor of intensive end-of-life care, over and above ... socio-demographic characteristics and patient preferences. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3624/abstract>

Association between quality of end-of-life care and possible complicated grief among bereaved family members

JOURNAL OF PALLIATIVE MEDICINE | Online – 22 July 2014 – Little is known about the association between quality of end-of-life care [QEOLC] of a patient and complicated grief among bereaved family members. Possible complicated grief was observed in 24.5% of the [study] participants. Dissatisfaction with the explanation to the family about the patient's expected outcome, unreasonable cost of care, and family's perception the deceased person had not achieved a sense of completion about his or her life, were significantly associated with possible complicated grief. Spousal relationship, primary caregiver, and high psychological distress had significant association. Perceptions on QEOLC were significantly associated with complicated grief. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0552>

Of related interest:

- *GRIEF MATTERS: AUSTRALIAN JOURNAL OF GRIEF & BEREAVEMENT*, 2014;17(1):18. **'Engaging organisations to support bereaved employees.'** Compelling reasons exist for organisations to plan for and manage grief and bereavement in the workplace. Grief is known to affect an individual's concentration and decision making and can cause stress and fatigue. Therefore, grief can impact on business activity and workplace dynamics. It has been suggested loyalty, retention, cohesiveness, business productivity, project continuity and organisational culture are improved when grief is adequately attended to... Although research is scarce, bereavement practitioners are active in promoting compassionate and supportive workplaces on the basis that doing so is good for the bereaved employee and, in-turn, good for business... <http://search.informit.com.au/documentSummary;dn=234598924746603;res=IELHEA>

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

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

Palliation and the caring hospital – filling the gap

JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS EDINBURGH, 2014;44(2):98-102. Palliation literally means comfort for the ill, but many in the general public as well as health professionals don't understand exactly what palliative care is. The most widely held ... view is that it is care at the very last stage of life, around the time of death. However, palliative care as more recently defined is moving away from treating just the imminently dying to those patients with any serious or life-threatening illness, who need relief from symptoms, pain or distress, at any point from diagnosis to death. While this much broader definition is a long way from the original idea of terminal care, it unquestionably includes it. It is easy to get "stuck" discussing definitions of palliative care, but there is greater agreement about its goals: a shift in focus from cure to palliation and an emphasis on maximising quality of life. This involves experienced, skilled management of pain and other distressing symptoms; ex-

pertise in acknowledging when a patient may be dying; and, a willingness to discuss what is happening with the patient and their family and helping them plan for future care. http://www.rcpe.ac.uk/sites/default/files/levack_2.pdf

Extract from *Journal of the Royal College of Physicians Edinburgh* article:

Taking an integrative approach, an acute palliative care unit, designated specialist palliative care beds or a designated ward will not look like a hospital nor will it look like a hospice, it will be something in between. Operating within the hospital organisational structure and with local expertise, it can be a test for palliative care provision and research, a pragmatic approach appropriate to the individual hospital and its patient population. There is a gap in care, and it urgently requires a creative solution.

College of Physicians & Surgeons of Ontario poll reveals Canadians support doctors' moral right to deny treatment

THE MEDICAL POST (Canada) | Online – 24 July 2014 – An unscientific poll suggests that Canadians support a doctor's right to refuse some procedures on the grounds of moral beliefs. The new stats from the College ... tallied up some 14,000 votes, giving the edge to the doctor's beliefs. The poll asked: "Do you think a physician should be allowed to refuse to provide a patient with a treatment or procedure because it conflicts with the physician's religious or moral beliefs?" So far, about 56% of respondents (8,331 votes) have said "yes." Meanwhile, 43% (or about 6,400 votes) have said "no." The rest picked "Don't know." The poll comes as the College reviews its human rights policies. <http://www.canadianhealthcarenetwork.ca/physicians/news/cpso-poll-reveals-canadians-support-doctors-moral-right-to-deny-treatment-35249>

Caring for the "hidden patient" after stroke

MEDSCAPE | Online – 22 July 2014 – Post stroke interventions that combine skill-building, such as problem-solving and stress management, with practical education may improve quality of life for both stroke survivors and their caregiver, concludes a new American Heart Association/American Stroke Association Scientific Statement. The new evidence helped lay the groundwork for recommendations for caregiver programs that improve care of stroke survivors and their families. The review and the recommendations ... was published online...¹ "Family caregivers are really the hidden patients here," said lead reviewer Tamilyn Bakas, professor and chair, Department of Science of Nursing Care, Indiana University School of Nursing... "They provide a level of care for the stroke survivor, but they have to attend to their own health care needs and their own physical and mental well-being," so they can continue to provide care. Caregiver stress is a leading cause of stroke survivor institutionalization, which results in substantial costs to the healthcare system, they note. <http://www.medscape.com/viewarticle/828687?src=rss>

Cont.

1. 'Evidence for Stroke Family Caregiver and Dyad Interventions: A Statement for Healthcare Professionals From the American Heart Association and American Stroke Association,' *Stroke*, 17 July 2014. A critical analysis of 17 caregiver intervention studies and 15 caregiver/stroke survivor dyad intervention studies was conducted to provide evidence-based recommendations for implementation and future design of stroke family caregiver and dyad interventions. <http://stroke.ahajournals.org/content/early/2014/07/17/STR.000000000000033.full.pdf+html>

Noted in Media Watch, 16 December 2013, #336 (p.13):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 9 December 2013 – **'Hidden patients: The relatives of patients in need of palliative care.'** When identifying patients for palliative care, medical specialists find it necessary to disclose "hidden" patients: the patient's relatives. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0333>

Noted in Media Watch, 14 February 2011, #188 (p.11, under 'Worth Repeating'):

- *CANADIAN JOURNAL OF PSYCHIATRY*, 2004;49(6):359-365. **'Palliative care for families: Remembering the hidden patients.'** This article briefly synthesizes empirical work that suggests how to best support families in a palliative care context. The authors discuss how to define the family, emphasizing a systems approach to family care. They describe the impact of the illness on the family in terms of family members' health, family communication issues, psychological issues, needs for information, physical care demands, and family costs of caring. <https://ww1.cpaapc.org/Publications/Archives/CJP/2004/june/kristjanson.pdf>

Using continuous sedation until death for cancer patients: A qualitative interview study of physicians' and nurses' practice in three European countries

PALLIATIVE MEDICINE | Online – 25 July 2014 – U.K. respondents reported a continuum of practice from the provision of low doses of sedatives to control terminal restlessness to rarely encountered deep sedation. In contrast, Belgian respondents predominantly described the use of deep sedation, emphasizing the importance of responding to the patient's request. Dutch respondents emphasized making an official medical decision informed by the patient's wish and establishing that a refractory symptom was present. Respondents employed rationales that showed different stances towards four key issues: the preservation of consciousness, concerns about the potential hastening of death, whether they perceived continuous sedation until death as an "alternative" to euthanasia and whether they sought to follow guidelines or frameworks for practice. <http://pmj.sagepub.com/content/early/2014/07/24/0269216314543319.abstract>

Noted in Media Watch, 21 July 2014, #367 (p.13):

- *SUPPORTIVE CARE IN CANCER* | Online – 15 July 2014 – **'Making sense of continuous sedation in end-of-life care for cancer patients: An interview study with bereaved relatives in three European countries.'** Relatives' descriptions of the practice referred to the outcome, to practical aspects, and to the goals of sedation. While most relatives believed sedation had contributed to a "good death" for the patient, many expressed concerns. These related to anxieties about the patient's wellbeing, their own wellbeing, and questions about whether continuous sedation had shortened the patient's life (mostly in the U.K.), or whether an alternative approach would have been better. Such concerns seemed to have been prompted by relatives witnessing unexpected events such as the patient coming to awareness during sedation. <http://link.springer.com/article/10.1007/s00520-014-2344-7>



World hospice &
palliative care day

11 October 2014

Who Cares? We Do!

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

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

Understanding patient perceptions of shared decision making

PATIENT EDUCATION & COUNSELING | Online – 21 July 2014 – [In this study] patients' conceptual definition of shared decision making (SDM) included four components of an interactive exchange prior to making the decision: 1) both doctor and patient share information; 2) both are open-minded and respectful 3) patient self-advocacy; and, 4) a personalized physician recommendation. Additionally, a long-term trusting relationship helps foster SDM. In contrast, when asked about a specific decision labeled as shared, patients described a range of interactions with the only commonality being that the two parties came to a mutually agreed-upon decision. There is no one-size-fits all process that leads patients to label a decision as shared. Rather, the outcome of "agreement" may be more important than the actual decision-making process for patients to label a decision as shared. Studies are needed to better understand how longitudinal communication between patient and physicians and patient self-advocacy behaviors affect patient perceptions of SDM. [http://www.pec-journal.com/article/S0738-3991\(14\)00291-2/abstract](http://www.pec-journal.com/article/S0738-3991(14)00291-2/abstract)

Of related interest:

- *JOURNAL FOR NURSE PRACTITIONERS* | Online – 15 July 2014 – '**Religious and spiritual differences within families: Influences on end-of-life decision making.**' Religious and spiritual diversity are increasing in the U.S. This can present unique challenges at the end of life, especially when individuals within the same family have differing beliefs. There are wide variations in individual interpretations of religious teachings. There is also a lack of homogeneity within religions. Health care providers may find it challenging to understand the nuances of individual religious traditions. Clinicians should approach patients and families with humility. A case is presented of a family with diverse traditions in Buddhism, Catholicism, and a non-religious spirituality. <http://www.sciencedirect.com/science/article/pii/S1555415514003821>

[Media Watch: Editorial Practice](#)

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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.

Improving inpatient hospice environments for older people in England: A documentary analysis

PROGRESS IN PALLIATIVE CARE, 2014;22(4):187-194. Four categories of building improvement were identified: 1) interior decoration or equipment; 2) public spaces; 3) private spaces; and, 4) health and safety. These improvements, while generally beneficial, were rarely targeted at older people. Most grant applicants stated that they had consulted service users, but only 13 specified that they consulted older people. Limited information was supplied about the methods or findings of these consultations. In 15 grant applications, older people were not mentioned at all. Older hospice inpatients, their relatives and advocacy groups should be involved more fully in decisions relating to the physical environment of care. Staff who prepare funding bids should receive training in conducting consultations with service users, and identifying and evaluating other relevant evidence. <http://www.maneyonline.com/doi/abs/10.1179/1743291X13Y.0000000073>

Selected articles on the architectural design of hospices and palliative care facilities noted in past issues of Media Watch:

- SINGAPORE | *The Straits Times* – 24 September 2013 – **'Today's hospices are built for yesterday.'** Dying patients and their family members lack adequate private spaces as hospices are not designed to support palliative care services. Some hospices are also isolated from the community as there are no communal spaces or facilities the public can opt to use.¹ [Noted in Media Watch, 30 September 2013, #325 (p.6)] <http://www.straitstimes.com/breaking-news/singapore/story/review-hospice-care-todays-hospices-are-built-yesterday-20130924>
 1. 'Hospitable Hospice: Redesigning Care for Tomorrow,' Lien Foundation, ACM Foundation. <https://www.dropbox.com/s/iwundjli0q6i854/HOSPITABLE%20HOSPICE%20I%20Ap.Issue%20&%20insights%20overview.pdf>
- *HEALTHCARE DESIGN* | Online – 11 April 2013 – **'Making space for hospice in the care continuum.'** Designing for the continuum of care – architecturally and clinically – is all the rage... Some designers and care organizations feel that hospice and palliative care have been tucked in the back corner of eldercare... [Noted in Media Watch, 15 April 2013, #301 (p.5)] <http://www.healthcaredesignmagazine.com/article/efa-2013-making-space-hospice-care-continuum>
- *QJM* (Quarterly Journal of Medicine) | Online – 13 March 2013 – **'Patient dying in hospital: An honoured guest in an honoured place?'** In *Modern Hospice Design: The Architecture of Palliative Care* (London: Routledge, 2009) Ken Worpole reviewed the architecture and design of hospital spaces in which the dying find themselves. The idea of hospital being an honoured place with dying patients as honoured guests opens a new window into our daily reality of working in hospitals. [Noted in Media Watch, 25 March 2013, #298 (p.10)] <http://qjmed.oxfordjournals.org/content/early/2013/03/13/qjmed.hct064.extract>
- *DESIGN & HEALTH* | Online – 2 September 2010 – **'Palliative care unit design: Patient and family preferences.'** The primary purpose of this qualitative study was to identify what palliative care patients and their families perceive to be important elements in the design of a palliative care unit for end-of-life care. [Noted in Media Watch, 6 September 2010, #165 (p.8)] <http://www.worldhealthdesign.com/Palliative-Care-Unit-Design.aspx>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BRITISH MEDICAL JOURNAL* | Online – 21 July 2014 – **'Assisted dying bill passes second reading in Lords, as support and opposition seem equally divided.'** The Assisted Dying Bill was given a second reading in the House of Lords will go on to its committee stage, after peers who oppose it accepted that it should be scrutinised further. Among more than 120 peers who spoke in the marathon second reading debate, opposition and support for the bill were split roughly 50:50. <http://www.bmj.com/content/349/bmj.g4739>

Cont.

- *CLINICS IN GERIATRIC MEDICINE*, 2014;30(3):553-576. **'Suicide in later life: Failed treatment or rational choice?'** This article discusses the effects that older adults' deaths through suicide, assisted dying, and physician-assisted dying have on survivors and the implications for clinical practice. [http://www.geriatric.theclinics.com/article/S0749-0690\(14\)00044-5/abstract](http://www.geriatric.theclinics.com/article/S0749-0690(14)00044-5/abstract)
- *INTERNATIONAL JOURNAL OF HUMAN RIGHTS* | Online – 17 July 2014 – **'The right to assisted suicide in the case law of the European Court of Human Rights.'** The case law of the European Court of Human Rights seems to be progressively outlining a right to assisted suicide, which would fall in the scope of the right to private life. The court modifies the ground of dignity: it is no more inherent to human nature, but linked to each individual's perception of dignity. <http://www.tandfonline.com/doi/abs/10.1080/13642987.2014.926891#.U85pDONdX8k>

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International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/5/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>

- *JOURNAL OF THE ROYAL COLLEGE OF PHYSICIANS EDINBURGH*, 2014;44(2):134-138. **'Assisted death: A basic right or a threat to the principal purpose of medicine?'** Sir Graeme Catto argues that terminally ill mentally competent adults should be able to choose the time and place of their death. Opposing him, Baroness Iora Finlay argues that both the Assisted Suicide (Scotland) Bill and Lord Falconer's private member's bill in the House of Lords endanger patients' safety and require doctors to assess patients against criteria that cannot be verified. http://www.rcpe.ac.uk/sites/default/files/current_controversy_0.pdf
- *MEDICOLEGAL & BIOETHICS* | Online – 17 July 2014 – **'Euthanasia and assisted suicide: A physician's and ethicist's perspectives.'** The authors ... examine the standard arguments advanced by both proponents and opponents of legalizing euthanasia and note some recent legal developments in the matter. They consider an aspect of the debate often underappreciated; that is, the wider consequences that legalizing euthanasia might have on the medical profession, the institutions of law and medicine, and society as a whole. The line of argument that connects this narrative and supports their rejection of euthanasia is the belief that intentionally inflicting death on another human being is inherently wrong. Even if it were not, the risks and harms of legalizing euthanasia outweigh any benefits. Ethical alternatives to euthanasia are available, or should be, and euthanasia is absolutely incompatible with physicians' primary mandate of healing. file:///C:/Users/Barry/Downloads/MB-59303-euthanasia-and-assisted-suicide_071714.pdf

Worth Repeating

Cultural diversity at the end of life: Issues and guidelines for family physicians

AMERICAN FAMILY PHYSICIAN, 2005;71(3):515-522. Ethnic minorities currently compose approximately one third of the population of the U.S. The U.S. model of health care, which values autonomy in medical decision making, is not easily applied to members of some racial or ethnic groups. Cultural factors strongly influence patients' reactions to serious illness and decisions about end-of-life care. Research has identified three basic dimensions in end-of-life treatment that vary culturally: 1) communication of "bad news"; 2) locus of decision making; and, 3) attitudes toward advance directives and end-of-life care. In contrast to the emphasis on "truth telling" in the U.S., it is not uncommon for health care professionals outside the U.S. to conceal serious diagnoses from patients, because disclosure of serious illness may be viewed as disrespectful, impolite, or even harmful to the patient. With regard to decision making, the U.S. emphasis on patient autonomy may contrast with preferences for more family-based, physician-based, or shared physician- and family-based decision making among some cultures. Data suggest lower rates of advance directive completion among patients of specific ethnic backgrounds, which may reflect distrust of the health care system, current health care disparities, cultural perspectives on death and suffering, and family dynamics. <http://marianjoylibrary.org/Diversity/documents/CulturalDiversityattheEndofLifeIssuesandGuidelines.pdf>

Editorial

Moving beyond cultural stereotypes in end-of-life decision making

AMERICAN FAMILY PHYSICIAN, 2005;71(3):429-430. Imagine all of our patients are invited to attend a "cultural competence" workshop called 'Understanding the Medical Culture,' where they will learn how the strange and mysterious environment of medical practice affects physicians, so that their otherwise incomprehensible behavior seems at least somewhat understandable. They will be offered handy tips that would allow them to predict physicians' behavior, such as... <http://www.aafp.org/afp/2005/0201/p429.html>

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