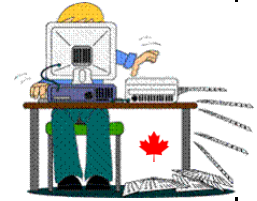


Media Watch...

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

Pediatric palliative care: Scroll down to [Specialist Publications](#) and 'Talking with parents about end-of-life decisions for their children' (p.12), in *Pediatrics*.

Canada

Predatory journals take a bite out of scholarship

THE GLOBE & MAIL | Online – 3 January 2015 – The academic imperative "publish or perish" is so well known that people with no intention of entering scholarly life are familiar with it – no tenure for you, my friend, without at least a handful of citations. The journals should be reputable and selective, as all the best ones are, but in the crunch quantity might just trump quality. Alas, now comes this new storm on the horizon of university careerists: predatory journals. Nobody inside academic life will consider it news that the number of journals, in almost every field, has risen in the post-print era. The good ones remain, and sometimes even retain a print version, but they are now flanked by opportunistic newcomers who prey on the desires of tenure-seeking scholars. That, in itself, is no big deal. A new journal can publish work as accomplished as an established one, assuming the usual practices of double-blind peer review: The reviewers, assumed to be experts in the field, don't know the identity of

the author, and the author doesn't know who the reviewers are. In my field, philosophy, acceptance rates at good journals run to about 5%, or one in 20 of submitted pieces, and rare is the article that goes into print without extensive revisions suggested by the reviewers. Predatory journals are a whole different beast. Instead of you seeking their grudging approval, they come after you. <http://www.theglobeandmail.com/globe-debate/predatory-journals-take-a-bite-out-of-scholarship/article22275403/>

Specialist Publications

'Authors and readers beware the dark side of Open Access' (p.10), in *Journal of Advanced Nursing*.

'If it looks like a duck and quacks like a duck ...' (p.10), in *Oncology Nursing Forum*.

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Noted in Media Watch, 13 October 2014, #379 (p.9):

- *JOURNAL OF THE ROYAL SOCIETY OF MEDICINE*, 2014;107(10):384-385. **'Science for sale: The rise of predatory journals.'** A new threat has emerged to the integrity of academic publishing: predatory journals. These unscrupulous publishers are exploiting the open-access model by corrupting the peer-review process, which is often absent or minimal. Their motivation is the procurement of evaluation and publication fees, which in the absence of traditional subscription rates are necessary to cover operating costs. Some claim to assess submissions within seventy-two hours and digitally publish them upon acceptance and receipt of the fee <http://jrs.sagepub.com/content/107/10/384.full>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 5 January 2015 – **'Supreme Court preparing landmark ruling on euthanasia and assisted suicide.'** The Supreme Court of Canada is preparing to issue a landmark ruling on euthanasia and physician assisted suicide, marking the first time the top court has addressed the issue since 1993, when it upheld the criminal ban in the case of Sue Rodriguez. No date has been set for the decision, but the court has asked interveners for their consent to a media preview, a routine practice for such high profile cases... The case is an appeal of a ruling by the British Columbia Court of Appeal, which overturned the victory at trial of the appellant Gloria Taylor. She and others convinced a lower court that the criminal law against assisting someone to commit suicide violated her right to life, liberty and security of the person, and her equality rights to be free of discrimination based on physical disability. Ms. Taylor, who had ALS, died soon after the ruling of an infection. She was joined in the case by Lee Carter, the daughter of Kay Carter, one of the few Canadians known to have died in the Dignitas assisted suicide clinic in Switzerland. The Supreme Court case is broader, and looks at whether several criminal laws apply to physician assisted death, and whether they should. <http://news.nationalpost.com/2015/01/05/supreme-court-preparing-landmark-ruling-on-euthanasia-and-assisted-suicide/>

Noted in Media Watch, 29 September 2014, #377 (p.2):

- BRITISH COLUMBIA | *The Times-Colonist* (Vancouver) – 20 September 2014 – **'What has changed since Sue Rodriguez?'** In 1993, Sue Rodriguez, suffering unbearably from ALS, challenged the Supreme Court of Canada to let her doctor help her die. The court denied her request, not because it wasn't the best option for her, but because of the fear that some vulnerable person somewhere, sometime, might be adversely affected by the repercussions of allowing Rodriguez a choice in dying. Lacking hard data to guide their discussion, the judges were clearly divided and ruled five to four against assisted dying. <http://www.timescolonist.com/opinion/op-ed/comment-what-has-changed-since-sue-rodriguez-1.1381969>

Noted in Media Watch, 14 October 2013, #327 (p.2):

- BRITISH COLUMBIA | CBC News (Vancouver) – 10 October 2013 – **'Doctor-assisted suicide ban upheld in B.C.'** The B.C. Court of Appeal ... has affirmed the law against assisted suicide, in a controversial and historic right-to-die case. ALS patient Gloria Taylor of Kelowna won a landmark ruling when a B.C. Supreme Court judge struck down Canada's law that made doctor-assisted suicide illegal. <http://www.cbc.ca/news/canada/british-columbia/doctor-assisted-suicide-ban-upheld-in-b-c-1.1958888>

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>



U.S.A.

Tomorrow's nursing homes must integrate palliative care

MCKNIGHT'S LONG TERM CARE NEWS | Online – 9 January 2015 – The number of people living in long-term nursing facilities in the U.S. is expected to double to more than three million by 2030, while more than forty percent of adults will die there. Increasingly, nursing homes are responsible for both the long-term management of patients with multiple complex and chronic illnesses, and the care of these individuals at the end of life. Today's nursing homes are falling short on delivering the high quality care their residents deserve. Limited resources, overwhelmed and undertrained frontline staff, and beleaguered leadership are all part of the problem. Inadequate pain management in nursing homes is common and well documented, as are pressure ulcers, the use of physical and chemical restraints and feeding tubes. Little attention is given to advance care planning, hospice referrals are often made too late or not at all, and repeated

avoidable hospitalizations are widespread. <http://www.mcknights.com/diane-e-meier-md-facp/article/391683/>

Specialist Publications

'End-of-life care in critical condition' (p.7), in *American Journal of Public Health*.

'Nearly half of all Medicare hospice enrollees received care from agencies owned by regional or national chains' (p.8), in *Health Affairs*.

'The invisible homebound: Setting quality-of-care standards for home-based primary and palliative care' (p.8), in *Health Affairs*.

'Futile-care theory in practice: A look at the law in Texas' (p.11), in *National Catholic Bioethics Quarterly*.

End-of-life instructions find no place in electronic health records

POLITICO | Online – 9 January 2015 – The federal government has spent billions helping doctors and hospitals digitize patients' lives, but there are still many holes in our electronic records including a big one: We can't list end-of-life wishes. Recording the desires of patients who are on their death beds – or even noting whether a patient has appointed someone to make medical decisions on his or her behalf – has become a huge gap in the nationwide effort to computerize patient care. The few hospitals trying to come up with their own digital approaches are finding it's not easy. Some physicians and health care experts who work on end-of-life sense timidity, a fear of going back into "death-panel territory" that has made it toxic to talk about, let alone make policy for, the needs of an aging population. There was nothing in the law that released spending for electronic records that prohibited them from recording end-of-life wishes, but other patient data were prioritized. <http://www.politico.com/story/2015/01/end-of-life-instructions-ehr-114139.html>

State Supreme Court to hear arguments in teen's battle over forced chemo

CONNECTICUT | *The Hartford Courant* – 8 January 2015 – For the state's child-protection agency and the cancer doctors at Connecticut Children's Medical Center [CCMC], there is no debate: 17-year-old Cassandra C. will die of Hodgkin's lymphoma without chemotherapy, and the teen doesn't have the legal standing to reject the treatments on her own. But at a ... hearing ... before the state Supreme Court, the justices will consider the constitutional argument from lawyers for Cassandra and her mother, Jackie Fortin, who supports her daughter's decision to reject chemotherapy treatments. The Department of Children & Families won temporary custody of Cassandra at the Superior Court level and Cassandra ... has been receiving regular treatments for more than four weeks at CCMC. The question, says Cassandra's lawyer, Assistant Public

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Defender Joshua Michtom, is whether, despite an encouraging prognosis, "a smart and knowledgeable 17-year-old (can) make the same choice, for better or worse, than she would be able to make without state interference nine months from now, when she turns 18," said Michtom. <http://www.courant.com/news/connecticut/hc-teen-battles-chemo-order-0103-20150102-story.html>

Of related interest:

- CONNECTICUT | NPR News – 8 January 2015 – **'Can Connecticut force a teenage girl to undergo chemotherapy?'** This is the first time a case like this has come up in Connecticut, but other states have considered the question ... [for example] ... Illinois and Maine ... where courts decided that even though teenagers who weren't yet 18 had refused treatment or didn't want to be kept alive artificially, there was evidence to show they were mature enough when they conveyed their wishes. <http://www.npr.org/blogs/health/2015/01/08/375659085/can-connecticut-force-a-teenage-girl-to-undergo-chemotherapy>

Here are the hospices that break the most rules

THE HUFFINGTON POST | Online – 8 January 2015 – Missed appointments. Confidential records left out in the open, in shopping bags and stacked on shelves. A patient overdosed with 10 times the amount of prescribed pain medication. These are some of the more than 31,000 violations turned up over the past decade by inspectors who oversee the nation's sprawling network of more than 4,000 hospices, which provide end-of-life comfort care to more than 1 million patients a year. Yet as the *Post* revealed last week, hospices that are docked for major violations during inspections are almost never punished.¹ Since 2004, state health officials have conducted about 15,000 hospice inspections to confirm that they are following rules set by Medicare's federal regulator. Yet The Centers for Medicare & Medicaid Services has punished just 16 hospices in the last decade for breaking health and safety standards. Some hospice violations, known as deficiencies, are minor. http://www.huffingtonpost.com/2015/01/08/hospice-rules_n_6418948.html

1. 'When hospices mistreat the dying, they almost never get punished,' *The Huffington Post*, 30 December 2014. <http://projects.huffingtonpost.com/hospice-inc/top-offending-hospices-rarely-punished>

Noted in Media Watch, 23 June 2014, #363 (p.2):

- *THE HUFFINGTON POST* | Online – 19 June 2014 – **'How dying became a multibillion-dollar industry.'** The U.S. hospice industry has quadrupled in size since 2000. Nearly half of all Medicare patients who die now do so as a hospice patient – twice as many as in 2000, government data shows. Since 2006, the U.S. government has accused nearly every major for-profit hospice company of billing fraud. <http://projects.huffingtonpost.com/hospice-inc>

Lots of responsibility for in-home care providers – but no training required

CALIFORNIA | *Kaiser Health News* – 6 July 2015 – No overall training is required for the more than 400,000 caregivers in California's \$7.3 billion In-Home Supportive Services Program for low-income elderly and disabled residents. Without instruction even in CPR or first aid, these caregivers can quickly become overwhelmed and their sick or disabled clients can get hurt, according to interviews with caregivers, advocates and elder abuse experts. The need for in-home caregivers is rising as the elderly and disabled population grows. The demand for personal aides – most of who work in the home – is expected to increase by 37% over the next decade, requiring about 1.3 million new positions... The federal government is trying to meet that need by stepping up efforts to expand and train the work force. But for now, there are no federal training requirements for in-home-caregivers. It's up to states to set them in Medicaid-funded programs like California's. As a result, training policies vary dramatically. <http://kaiserhealthnews.org/news/lots-of-responsibility-for-in-home-care-providers-but-no-training-required/>

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Representative sample of articles on the need to educate and train family caregivers:

- *FORBES* | Online – 4 June 2014 – '**Finally, some help for family caregivers after hospital discharges.**' Two models have surfaced that will begin engaging family caregivers in hospital discharges, and give them the information and training that they need to care for their loved ones once they return home. [Noted in Media Watch, 9 June 2014, #361 (p.3)] <http://www.forbes.com/sites/howardgleckman/2014/06/04/finally-some-help-for-family-caregivers-after-hospital-discharges/>
- OKLAHOMA | *Tulsa World* – 16 March 2014 – '**An army of caregivers with no basic training.**' At 600,000 strong, family caregivers in Oklahoma outnumber the entire active-duty U.S. Army. They've ... tasked themselves with helping friends or relatives stay in the place they most want to be – home. Yet many ... feel overwhelmed and ill-equipped to deal with the needs of those they help... This challenge is not lost on Senator Brian Crain ... who is pushing Senate Bill 1536, which would make sure that family caregivers receive the training they need to care properly for their loved ones after they leave a hospital [Noted in Media Watch, 24 March 2014, #350 (p.4)] http://www.tulsaworld.com/opinion/juliedelcour/julie-delcour-an-army-of-caregivers-with-no-basic-training/article_56ab7207-d8c0-5c83-a89c-7f76136c2818.html

N.B. Senate Bill 1536 was passed into law in May 2014.
- *FORBES* | Online – 26 July 2011 – '**New stipend program for caregivers of veterans disperses first payments.**' Family members caring for veterans received their first payments from the U.S. Department of Veterans Affairs' Family Caregiver Program. Nearly 200 completed the required training program in time to receive a stipend... [Noted in Media Watch, 1 August 2011, #212 (p.4)] <http://blogs.forbes.com/bernardkrooks/2011/07/25/new-stipend-program-for-caregivers-of-veterans-disperses-first-payments/>

International

Cost of dying in the U.K.

Debt and buried: Soaring cost of funerals mean poor cannot afford to die

U.K. (England) | *The Mirror* – 6 January 2015 – The amount councils must spend on paupers' funerals has risen by more than a third since the Tories came to power – as campaigners warn the poor cannot afford to die. Public health funerals cost £3.4 million last year, a 36% increase on the £2.5 million in 2010. There was also a rise in the number of such burials over the same period from 3,177 to 3,495. Paupers funerals are paid for by local authorities when someone has died without relatives or money, or when relatives have been unable to fund the service. <http://www.mirror.co.uk/news/uk-news/debt-buried-soaring-cost-funerals-4925657>

Noted in Media Watch, 27 October 2014, #381 (p.6):

- U.K. | *The Guardian* – 20 October 2014 – '**The return of the pauper's funeral to austerity Britain.**' Funeral poverty is a potent indicator of the combined impact of recession, austerity, low wages and the insecure job market. One in seven people struggle to pay funeral costs. <http://www.theguardian.com/society/2014/oct/20/paupers-funeral-austerity-britain-soaring-costs-bury-loved-ones>

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.

End-of-life care in Scotland

Shock over number of Highland hospital bed blocking deaths

U.K. (Scotland) | *The Press & Journal* (Aberdeen) – 6 January 2015 – Shock new figures revealed nearly 100 people needlessly languishing in Highland hospitals died before they could be released. Official bed blocking statistics show that dozens of patients clinically ready to leave wards were left stranded because of a care crisis in the north. The bed blocking figures show 33 people died in Highland hospitals in 2012-2013 because of a shortage of care home places or care at home provision. The Scottish Government insisted tackling delayed discharges was a "top priority" and has allocated £18 million to health boards to help

ease the problem. The Scottish Government recently awarded National Health Service Highland £307,500 to tackle bed blocking. <https://www.pressandjournal.co.uk/fp/news/politics/holyrood/447720/shock-over-number-of-highland-hospital-bed-blocking-deaths/>

Quote from *The Press & Journal* report

Hospital is not the right place for palliative care ... many people wish to die at home or in a homely setting rather than in a busy ward.

End-of-life care in the England

Free end-of-life care priced at £200 million

U.K. (England) | *Local Government Chronicle* – 5 January 2015 – A Labour plan for free end-of-life social care could cost £200-£250 million annually to implement, the Treasury has claimed. The estimate refers to the cost of supplying free social care, excluding living costs, for people who have been diagnosed as having less than a year to live and are on the National Health Services End of Life register, on which people remain for an average of three months before dying. It assumes the policy would begin in April 2015 and that the Dilnot cap on care costs would be introduced in 2016.¹

The report warned "substantial caveats" must be applied to the figure. <http://www.lgcplus.com/topics/social-care/free-end-of-life-care-priced-at-200m/5077962.article>

Specialist Publications

'Will having a named general practitioner for older people improve care and reduce hospital admissions in England?' (p.11), in *Journal of Ambulatory Care Management*.

1. 'Fairer Care Funding: The Report of the Commission on Funding of Care & Support,' July 2011. Commission chair: Sir. Andrew Dilnot. [Noted in Media Watch, 11 July 2011, #209 (p.5)] <http://yhsccommissioning.org.uk/FairerCareFundingReport.pdf>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (Scotland) | *Glasgow South & Eastwood Extra* – 8 January 2015 – **'Committee reports on suicide Bill.'** Holyrood's Justice Committee has reported on the practical and legal issues at the centre of a Bill to legalise assisted suicide. Scrutiny of the proposed legislation, which would allow those with terminal or life-shortening illnesses to obtain help in ending their suffering, will begin at the Health Committee next week. Members will also consider the Justice Committee's report, which raises a number of concerns about the Assisted Suicide Bill, including the need for clarity around the role of the "facilitator" who would help the terminally ill person end their life, and time limits related to requests and the act of suicide itself. <http://www.glasgowsouthandeastwoodextra.co.uk/news/scottish-headlines/committee-reports-on-suicide-bill-1-3654855>

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

Ethical obligations and clinical goals in end-of-life care: Deriving a quality-of-life construct based on the Islamic concept of accountability before God (*Taklif*)

AMERICAN JOURNAL OF BIOETHICS, 2015;15(1):3-13. End-of-life medical decision making presents a major challenge to patients and physicians alike. In order to determine whether it is ethically justifiable to forgo medical treatment in such scenarios, clinical data must be interpreted alongside patient values, as well as in light of the physician's ethical commitments. Though much has been written about this ethical issue from religious perspectives (especially Christian and Jewish), little work has been done from an Islamic point of view. To fill the gap in the literature around Islamic bioethical perspectives on the matter, the authors derive a theologically rooted rubric for goals of care. They use the Islamic obligation for Muslims to seek medical treatment as the foundation for determining the clinical conditions under which Muslim physicians have a duty to treat. <http://www.tandfonline.com/doi/abs/10.1080/15265161.2014.974769>

N.B. This issue of the *American Journal of Bioethics* includes several articles on end-of-life care from the Islamic perspective. Journal contents page: <http://www.tandfonline.com/toc/uajb20/current>. Additional articles on the subject are noted in Media Watch 15 December 2014, #388 (pp.11-12), 16 June 2014, #362 (p.11), and 28 March 2011, #194 (p.10).

End-of-life care in critical condition

AMERICAN JOURNAL OF PUBLIC HEALTH, 2015;105(1):58-61. A discussion of misconceptions which members of the general public and medical professionals have about the terms palliative care, hospice and comfort measures, and of cultural norms and societal taboos related to end of life care, is presented. <http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2014.302189>

Views and experiences of using integrated care pathways (ICPs) for caring for people in the last days to hours of life: Results from a cross-sectional survey of U.K. professionals

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 6 January 2015 – Ninety-three per cent (1138/1228) of respondents used the Liverpool Care Pathway (LCP) or local variant. Eighty-eight per cent (1089/1234) felt ICPs enabled professionals to provide better care for individuals and their families/carers. ICPs were viewed as promoting patient-centred holistic care, improving pain and symptom control, providing guidance and standards and improving communication with patients/families. Sixty-two per cent (770/1234) had no concerns regarding the use of ICPs. Areas of concern included incorrect use and implementation of the ICP, poor communication with families, junior level staff making decisions and insufficient education and support. There was strong support for using ICPs for caring for people in the last days to hours of life. ICPs were viewed as supporting high-quality patient-centred holistic care. Given the recommendations of the More Care Less Pathway report,¹ those that develop the guidance and support that replace the LCP need to incorporate the aspects of this that have resulted in the benefits seen by professionals within this survey, but also learn from the instances where ICPs have failed to prevent poor care, or worse, have contributed to it. <http://spcare.bmj.com/content/early/2015/01/06/bmjspcare-2014-000768.abstract>

1. 'More Care, Less Pathway: Review of Liverpool Care Pathway for Dying Patients,' Department of Health, July 2013. [Noted in Media Watch, 22 July 22 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

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

Nearly half of all Medicare hospice enrollees received care from agencies owned by regional or national chains

HEALTH AFFAIRS, 2015;34():30-38. Analyses of ownership in the U.S. hospice sector have focused on the growth of for-profit hospice care and on aggregate differences in patient populations and service use patterns between for-profit and not-for-profit agencies. Such comparisons, although useful, do not offer insights about the types of organizations within the hospice sector, including the emergence of multiagency chains. Using Medicare cost report data for the period 2000-2011, the authors tracked the evolution of the U.S. hospice industry. They not only describe the market's composition by profit status but also provide new information about the roles of regional and national chains. Almost half of all Medicare hospice enrollees in 2011 received hospice services from a multiagency chain. A handful of companies play a prominent role, although the presence of smaller for-profit and not-for-profit hospice chains also has grown in recent years. By focusing on the role of the diverse organizations that provide hospice care, our analyses can help inform efforts to monitor and assure quality of care, to assess payment adequacy and options for reform, and to facilitate greater transparency and accountability within the hospice marketplace. <http://content.healthaffairs.org/content/34/1/30.abstract?=&right>

Noted in Media Watch, 11 June 2012, #257 (p.11):

- *HEALTH AFFAIRS*, 2012;31(6):1286-1293. **'U.S. hospice industry experienced considerable turbulence from changes in ownership, growth, and shift to for-profit status.'** The One-fifth of Medicare-certified hospices active in 1999 had closed or withdrawn from the program by 2009, and more than 40% had experienced one or more changes in ownership. The most prominent trend was the shift in ownership type from non-profit to for-profit ownership. <http://content.healthaffairs.org/content/31/6/1286.abstract>

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

The invisible homebound: Setting quality-of-care standards for home-based primary and palliative care

HEALTH AFFAIRS, 2015;34(1):21-29. Approximately four million adults in the U.S. are homebound, and many of them cannot access office-based primary care. Home-based medical care can improve outcomes and reduce health care costs, but this care operates in a quality measurement desert, having been largely left out of the national conversation on care quality. To address this shortcoming, two of the authors created the National Home-Based Primary & Palliative Care Network, an organization whose members include exemplary home-based medical practices, professional societies, and patient advocacy groups. This article describes the current status of home-based medical care in the U.S. and offers a brief narrative of a fictional homebound patient and the health events and fragmented care she faces. The article then describes the network's quality-of-care framework, which includes ten quality-of-care domains, thirty-two standards, and twenty quality indicators that are being tested in the field. The same two authors also developed a practice-based registry that will be used for quality-of-care benchmarking, practice-based quality improvement, performance reporting, and comparative effectiveness research. Together, these steps should help bring home-based medical care further into the mainstream of U.S. health care. <http://content.healthaffairs.org/content/34/1/21.abstract>

[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>

Defibrillator patients should not be denied a peaceful death

INTERNATIONAL JOURNAL OF CARDIOLOGY | Online – 5 January 2015 – Implantable Defibrillators (ICD) prevent sudden cardiac death. With declining health ICD therapy may prolong death and expose the patient to unnecessary pain and anxiety. Few studies have addressed end of life care in ICD patients. The objective of this study was to investigate end of life in ICD patients, with respect to location of death; duration between do-not-resuscitate-orders (DNR) and deactivation of ICD therapy or DNR and time of death. A descriptive analysis of 65 deceased ICD patients, all whom had a written DNR-order before death, is presented. The majority of ICD patients with a DNR-order were treated in university hospitals. More than half still had shock treatment active at time of death with a median of four days or more between DNR decision and death. Patients with therapy deactivated, two days or more elapsed in more than a third from DNR decision to deactivation of therapy, exposing patients to a high risk of painful shocks before death. [http://www.internationaljournalofcardiology.com/article/S0167-5273\(15\)00037-6/abstract](http://www.internationaljournalofcardiology.com/article/S0167-5273(15)00037-6/abstract)

Selected articles on defibrillator deactivation in end-of-life care noted in past issues of Media Watch:

- *PALLIATIVE MEDICINE* | Online – 19 September 2014 – **'Patients' perception of implantable cardioverter defibrillator deactivation at the end of life.'** Patients regard the implantable cardioverter defibrillator as a complex and solely beneficial device, with little insight regarding its potential impact on a peaceful death. This review confirms the need for professionals to discuss with patients and families implantable cardioverter defibrillator functionality and deactivation at appropriate opportunities. [Noted in Media Watch, 22 September 2014, #376 (p.14)] <http://pmj.sagepub.com/content/early/2014/09/17/0269216314550374.abstract>
- *JOURNAL OF CARDIAC FAILURE*, 2014;20(8):S11. **'Shared decision-making about end-of-life care for heart failure patients with an implantable cardioverter defibrillator: A national cohort study.'** Implantable cardioverter defibrillator recipients with heart failure hold many perceptions that could interfere with effective decision-making. [Noted in Media Watch, 11 August 2014, #370 (p.12)] [http://www.onlinejcf.com/article/S1071-9164\(14\)00269-3/fulltext](http://www.onlinejcf.com/article/S1071-9164(14)00269-3/fulltext)
- *PATIENT-PATIENT-CENTERED OUTCOMES RESEARCH* | Online – 26 March 2014 – **'Making decisions about implantable cardioverter-defibrillators from implantation to end of life: An integrative review of patients' perspectives.'** Patients faced with decisions often misunderstood the functionality of their ICD, or overestimated its benefit. They expressed mixed preferences for the desire to be involved in decisions. [Noted in Media Watch, 21 April 2014, #354 (p.13)] <http://link.springer.com/article/10.1007/s40271-014-0055-2#>
- *CURRENT HEART FAILURE REPORTS* | Online – Accessed 18 March 2014 – **'Ethical challenges of deactivation of cardiac devices in advanced heart failure.'** While patients with ICDs are routinely counseled with regard to the benefits of ICDs, they have a poor understanding of the options for device deactivation and related ethical and legal implications. [Noted in Media Watch, 24 March 2014, #350 (pp.9-10)] <http://link.springer.com/article/10.1007/s11897-014-0194-8>

Intensive care nurses' role in end-of-life decision-making: Findings from a grounded theory study in five countries

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online – 3 January 2015 – Intensive care units (ICUs) focus on treatment for those who are critically ill and interventions to prolong life. Ethical issues arise when decisions have to be made regarding the withdrawal and withholding of life-sustaining treatment and the shift to comfort and palliative care. These issues are particularly challenging for nurses when there are varying degrees of uncertainty regarding prognosis. Little is known about nurses' end-of-life (EoL) decision-making practice across cultures. The core category that emerged [in this study] was "negotiated reorienting." Whilst nurses do not make the "ultimate" EoL decisions, they engage in two core practices: consensus seeking (involving coaxing,

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information cuing & voice enabling) and emotional holding (creating time-space & comfort giving). There was consensus [among study participants] regarding the core concept and core practices employed by nurses in the ICUs in the five countries. However, there were some discernible differences regarding the power dynamics in nurse-doctor relationships, particularly in relation to the cultural perspectives on death and dying and in the development of palliative care. The research suggests the need for culturally sensitive ethics education and bereavement support in different cultural contexts. [http://www.journalofnursingstudies.com/article/S0020-7489\(14\)00333-2/abstract](http://www.journalofnursingstudies.com/article/S0020-7489(14)00333-2/abstract)

Of related interest:

- **CHRONIC ILLNESS** | Online – 7 January 2015 – '**Are nurses more likely to report providing care plans for chronic disease patients than doctors? Findings from a New Zealand study.**' The level of engagement of primary care nurses with chronic illness care was no surprise. The low number reporting they provided patients with a care plan, most of the time or always, was unexpected. Aspects of care planning, however, were reported as taking place more frequently. This discrepancy between the process of care planning and the outcome, a care plan, is not unique to this region of New Zealand and warrants further research. <http://chi.sagepub.com/content/early/2015/01/07/1742395314567479.abstract>

Authors and readers beware the dark side of Open Access

JOURNAL OF ADVANCED NURSING | Online – 13 December 2014 – The concept of predatory publishing has emerged from the open access publishing movement. The term "predatory open access," was introduced by University of Colorado librarian and researcher Jeffrey Beall, identifying the practices of some "publishing companies" of soliciting papers from authors for "publication" in journals that lack acceptable peer review, editorial oversight, or established procedures to protect against plagiarism, data duplication or other unethical practices. The difference between acceptable open access publishers and predatory publishers is that, while both operate on a pay-to-publish business model, predatory publishers do not follow many if not all acceptable publication standards. Predatory publishers have been known to claim to be "leading" publishers even though they may be just

starting. They list contact information that does not clearly indicate where they are located or use free email services for contact. Often, multiple journals from the same publisher will have the same editor and editorial board, and there have been reports of board members being appointed to these panels without their application or knowledge. <http://onlinelibrary.wiley.com/doi/10.1111/jan.12589/full>

Extract from *Journal of Advance Nursing* article

Predatory publishers have also been known to operate alongside predatory conference organisers and to tout the offer of publication in conference proceedings.

Of related interest:

- *ONCOLOGY NURSING FORUM*, 2015;42(1):9. '**If it looks like a duck and quacks like a duck ...**' Have you ever received an email inviting you to submit an article or edit an issue of a journal that sounds vaguely familiar? Do they recognize you as an expert in the field and shower you with compliments? Does your heart skip a beat, and do you feel flattered and think, yes, you will write that article? The invitation sounds great – a guaranteed two-week turnaround to publication and it seems to come from a senior academic, perhaps one you recognize as a big name in the field. So you write the article, your colleagues write their articles for the issue you are editing, and you work with them to make their manuscripts the best they can be. And then it all goes wrong. You receive an invoice for a large sum of money for the honor of publishing in the journal that you realize, too late, is not a legitimate journal after all. <http://ons.metapress.com/content/h75p916257355333/fulltext.pdf>

Will having a named general practitioner for older people improve care and reduce hospital admissions in England?

JOURNAL OF AMBULATORY CARE MANAGEMENT, 2015;38(1):10-15. In England, the Department of Health's planned introduction of a named and accountable family doctor (i.e., general practitioner) for patients older than 75 years is aimed at reducing the increasing number of unplanned hospital admissions observed in this group and driving down the associated health care costs. In this article, we explore the debate surrounding the plans and the potential impact of the contractual change on patients and health care practitioners, both intended and unintended. http://journals.lww.com/ambulatorycaremanagement/Abstract/2015/01000/Will_Having_a_Named_General_Practitioner_for_Older.4.aspx

Noted in Media Watch, 30 June 2014, #364 (p.11):

- *GP | Online* – 26 June 2014 – '**Liverpool Care Pathway successor "clarifies GP role," says Royal College of General Practitioners.**' 'Priorities for Care' restructure the approach to caring for people nearing the end of their life, placing greater emphasis on the wishes of the dying person and communication with their family.¹ The 'Priorities of Care' propose a named family doctor to take overall responsibility for the care of patients nearing the end of their lives. <http://www.gponline.com/liverpool-care-pathway-successor-clarifies-gp-role-says-rcgp/palliative-end-of-life-care/article/1300789?HAYILC=SHOWCASE>

1. 'One chance to get it right: Improving people's experience of care in the last few days and hours of life,' Leadership Alliance for the Care of Dying People, June 2014. <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

Futile-care theory in practice: A look at the law in Texas

NATIONAL CATHOLIC BIOETHICS QUARTERLY, 2014;14(4):619-624. Futile-care policies and laws unilaterally locate health care decision making in persons and committees other than the patient and his surrogate(s). Although not voluntarily ceded by the patient, this authority is assumed by third parties whose interests and goals do not contribute to the material and spiritual flourishing of the individual patient. A prime example is the Texas medical futility law, which blatantly disregards the natural right of patients to decide the course of their own health care. http://www.pdcnet.org/pdc/bvdb.nsf/purchase?openform&fp=ncbq&id=ncbq_2014_0014_0004_0619_0624

How death imitates life: Cultural influences on conceptions of death and dying

ONLINE READINGS IN PSYCHOLOGY & CULTURE, 2014;6(2). Regardless of how or where we are born, what unites people of all cultures is the fact everyone eventually dies. However, cultures vary in how they conceptualize death and what happens when a person dies. In some cultures, death is conceived to involve different conditions, including sleep, illness, and reaching a certain age. In other cultures, death is said to occur only when there is a total cessation of life. Similarly, certain cultural traditions view death as a transition to other forms of existence; others propose a continuous interaction between the dead and the living; some cultures conceive a circular pattern of multiple deaths and rebirths; and yet others view death as the final end, with nothing occurring after death. These different conceptions have a noticeable influence on their lifestyles, their readiness to die for a cause, the degree to which they fear death, their expressions of grief and mourning, and the nature of funeral rituals. Any reasonably broad conceptualization of death issues would necessarily have to incorporate these various cultural variations. <http://scholarworks.gvsu.edu/cgi/viewcontent.cgi?article=1120&context=orpc>

Talking with parents about end-of-life decisions for their children

PEDIATRICS | Online – 5 January 2015 – Retrospective studies show that most parents prefer to share in decisions to forgo life-sustaining treatment (LST) from their children. We do not yet know how physicians and parents communicate about these decisions and to what extent parents share in the decision-making process. Overall, 27 physicians participated [in this study], along with 37 parents of 19 children for whom a decision to withhold or withdraw LST was being considered. All physicians focused primarily on providing medical information, explaining their preferred course of action, and informing parents about the decision being reached by the team. Only in 2 cases were parents asked to share in the decision-making. Despite their intense emotions, most parents made great effort to actively participate in the conversation. They did this by asking for clarifications, offering their preferences, and reacting to the decision being proposed... In the few cases where parents strongly preferred LST to be continued, the physicians either gave parents

more time or revised the decision. Parents are able to handle a more active role than they are currently being given. Parents' greatest concern is their child might suffer. <http://pediatrics.aappublications.org/content/early/2015/01/01/peds.2014-1903.abstract>

Continuing education needs of pediatricians across diverse specialties caring for children with medical complexity

CLINICAL PEDIATRICS | Online – 5 January 2015 – Care for children with medical complexity relies on pediatricians who often are ill equipped, but striving to provide quality care. Pediatricians [i.e., survey respondents] recognized the need for skills in care coordination, giving bad news, working in interprofessional teams, and setting goals of care with patients. Incorporating basic palliative care education may fill an important training need across diverse pediatric specialties. <http://cpj.sagepub.com/content/early/2015/01/02/0009922814564049.abstract>

Representative sample of articles on end-of-life decisions for children living with a terminal illness noted in past issues of Media Watch:

- *JOURNAL OF MEDICAL ETHICS* | Online – 10 June 2014 – **'Parents who wish no further treatment for their child.'** Cases of parents who want treatment for their child to be withdrawn against the views of the medical team have not received much attention. Yet resolution of such conflicts demands much effort of both the medical team and parents. Sharing end-of-life decisions with parents is a more important duty for physicians than protecting parents from guilt or doubt. Moreover, a request from parents on behalf of their child to discontinue treatment is, and should be, hard to over-rule in cases with significant prognostic uncertainty and/or in cases with divergent opinions within the medical team. [Noted in Media Watch, 16 June 2014, #362 (p.9)] <http://jme.bmj.com/content/early/2014/06/10/medethics-2013-101395.abstract>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 April 2014 – **'Does decisional conflict differ across race and ethnicity groups? A study of parents whose children have a life-threatening illness.'** Significant differences exist by race, ethnicity, language spoken, and diagnosis time across several sub-domains of decisional conflict. These differences are important to address when creating clinical care plans, engaging in shared decision-making, and creating interventions to alleviate decisional conflict. [Noted in Media Watch, 14 April 2014, #353 (p.12)] <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0604>
- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 5 December 2013 – **'What parents want from doctors in end-of-life decision-making for children.'** The majority of parents [i.e., study participants] found their child's doctor enabled them to be the ultimate decision maker for their child, which was what they very clearly wanted to be, and consequently enabled them to exercise their parental autonomy. Parents found it problematic when doctors took over decision-making. A less frequently reported, yet significant role for doctors was to affirm decisions after they had been made by parents. [Noted in Media Watch, 9 December 2013, #335 (p.5)] <http://adc.bmj.com/content/early/2013/12/05/archdiscchild-2013-304249.abstract>

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- *FAMILIES, SYSTEMS, & HEALTH*, 2013;31(4):406-413. '**Perspectives of parents on making decisions about the care and treatment of a child with cancer: A review of literature.**' Seventeen articles were identified that focused specifically on the decisions parents make regarding the care and treatment of children with cancer. Coders agreed that the child's quality of life/well-being, parental hope/expectations, support/supportive care, communication, and information were important themes in considering the decisions parents made regarding the care and treatment of children with cancer. [Noted in Media Watch, 6 January 2014, #339 (p.12)] <http://psycnet.apa.org/journals/fsh/31/4/406/>
- *PROGRESS IN PALLIATIVE CARE* | Online – 15 October 2012 – '**The child's voice in pediatric palliative and end-of-life care.**' Although much is asked clinically and emotionally of children and adolescents who are receiving treatment for a life-threatening illness, they are not routinely asked how they experience the treatment that is intended to save or prolong their lives. The authors offer a description of the term "child's voice" and describe methods used to solicit and validate the ill child's reports of treatment-related symptoms and quality of life during palliative or end-of-life care. [Noted in Media Watch, 22 October 2012, #276 (p.9)] <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000035>

Palliative sedation: Clinical practice challenges in Mexico and development of a national protocol for Mexico

PROGRESS IN PALLIATIVE CARE | Online – 7 January 2015 – Given changes to Mexican law that have called for provision of adequate palliative care for all patients in Mexico, and advance care planning laws that allow patients to refuse medical treatments that are not consistent with their goals of care, this ... paper seeks to frame commonly articulated positions regarding PS [palliative sedation], explores these challenges in Mexico, and suggests putative guidelines for safe and appropriate implementation of PS. At the urging the Ministry of Health in Mexico, the authors present a cogent, evidence-based, and internationally vetted protocol outlining the indications for PS and suggested ... guidelines for safe and effective implementation of PS in Mexico for appropriate patients. <http://www.maneyonline.com/doi/abs/10.1179/1743291X15Y.0000000001>

Media Watch: Editorial Practice

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

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
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5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Cost-effectiveness of social work services in aging: An updated systematic review

RESEARCH ON SOCIAL WORK PRACTICE | Online – 30 December 2014 – This study examines the impact of social work interventions in aging on quality of life (QOL) and cost outcomes in four categories (health, mental health, geriatric evaluation and management, and caregiving). Seventy-one percent of the studies report significant QOL outcomes. Twenty-one studies include cost outcomes, with 15 documenting significant cost savings. The findings suggest that social work interventions in aging have a positive and significant impact on QOL and cost outcomes. Applications for social work

practice and research are discussed. <http://rsw.sagepub.com/content/early/2014/12/15/1049731514563578.abstract>

Extract from *Research on Social Work Practice* article

Twelve of the studies reporting significant cost outcomes examine social work interventions in health, including care coordination and end-of-life/palliative care.

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/01/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 | HPC Consultation Services (Waterloo Region/Wellington County): <http://hpcconnection.ca/general-resources/in-the-news/>

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://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

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>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *SOCIAL SCIENCE & MEDICINE* | Online – 29 December 2014 – '**Attitudes towards legalising physician provided euthanasia in Britain: The role of religion over time.**' The support for legalization rose from around 76.95% in 1983 to 83.86% in 2012. This coincided with an increase in secularization exhibited in the survey: the percentage of people with no religious affiliation increasing from 31% to 45.4%, and those who do not attend a religious institution (e.g., church) increasing from 55.7% to 65.03%. This study demonstrates an increase in the support of euthanasia legalisation in Britain in the last 30 years coincided with increased secularization. It does not follow, however, that trends in public support are immutable nor that a change in the law would improve on the current pragmatic approach toward hastening death by a physician adopted in England & Wales in terms of the balance between compassion and safeguards against abuse offered. <http://www.sciencedirect.com/science/article/pii/S0277953614008387>

Worth Repeating

Young caregivers in the end-of-life setting: A population-based profile of an emerging group

JOURNAL OF PALLIATIVE MEDICINE, 2010;13(10):1225-1235. Most active care [among study participants] was provided by older, close family members, but large numbers of young people (ages 15-29) also provided assistance to individuals with advanced life-limiting illness. They comprised 14.4% of those undertaking "hands-on" care on a daily or intermittent basis, whom the authors grouped together as active caregivers. Almost as many young males as females participate in active caregiving (men represent 46%); most provide care while being employed, including 38% who work full-time. Over half of those engaged in hands-on care indicated the experience to be worse or much worse than expected, with young people more frequently reporting dis-

satisfaction thereof. Young caregivers also exhibited an increased perception of the need for assistance with grief. Young people can be integral to end-of-life care, and represent a significant cohort of active caregivers with unique needs and experiences. <http://www.liebertonline.com/doi/abs/10.1089/jpm.2010.0004>

Extract from *Journal of Palliative Medicine* article

They [i.e., young caregivers] may have a more negative experience as caregivers, and increased needs for grief counseling services compared to other age cohorts of caregivers.

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net