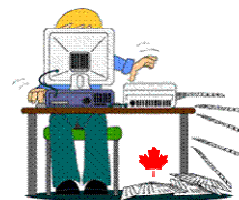


Media Watch...

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

10 March 2014 Edition | Issue #348



Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

Compiled & Annotated by Barry R. Ashpole

Physician-patient communication: Scroll down to [Specialist Publications](#) and 'When open-ended questions don't work: The role of palliative paternalism in difficult medical decisions' (p.12), in *Journal of Palliative Medicine*.

Canada

Twelve months later, Health Canada follows through on palliative care funds

ONTARIO | iPolitics (Ottawa) – 6 March 2014 – A year after promises were made in the 2013 budget, healthcare workers in palliative care will finally be receiving new funding for training and education. Health Minister Rona Ambrose announced \$3 million in funding over the next three years for the Pallium Foundation of Canada. The announcement follows through on a commitment made in the 2013 budget. The funding, Ambrose said ... will enable the foundation to help train and equip healthcare professionals in long-term care facilities, home-care and palliative care facilities across Canada. <http://www.ipolitics.ca/2014/03/06/twelve-months-later-health-canada-follows-through-on-palliative-care-funds/>

Home care client fears changes to system

MANITOBA | *The Winnipeg Free Press* – 4 March 2014 – The Winnipeg Regional Health Authority [WRHA] is in the final stages of switching home-care workers in Winnipeg to equivalent full-time (EFT) positions from part-time casual. The 37-year-old, who lives with spinal muscular atrophy, has been told there will be a lot of new faces who, at first, will have little knowledge about his care. Réal Cloutier, the WRHA's chief operating officer and VP for long-term and community care, said the move to EFT will improve conditions for home-care workers who can now count on a guaranteed income. The hope is there will be less staff turnover. Workers can request the number of hours per day they want to work and be scheduled to receive those hours. There are about 2,500 home-care workers and 14,000 clients affected by the EFT rollout, which is at the end of the WRHA's five-year implementation plan. <http://www.winnipegfreepress.com/local/home-care-client-fears-changes-to-system-248147311.html>

Specialist Publications

'Virtual mourning and memory construction on Facebook: Here are the terms of use' (p.11), in *Bulletin of Science Technology Society*.

N.B. Co-author Rhonda McEwen was interviewed 4 March 2014 on CBC's Metro Morning program: <http://www.cbc.ca/metromorning/episodes/2014/03/05/social-media-mourning/>

U.S.A.

Guidelines will help end-of-life oversight

PENNSYLVANIA | *The Philadelphia Inquirer* – 6 March 2014 – When the hospice nurse called police in the assisted-suicide case of Barbara Mancini, David Casarett knew he had work to do. He feared the actions of one hospice nurse could discourage Americans from using that model of palliative care for the terminally ill, or inhibit dying people in pain from taking morphine. So Casarett, a University of Pennsylvania physician and chief medical officer of Penn-Wissahickon Hospice, teamed with law professor Thaddeus Pope, formerly of Widener University and an expert in end-of-life law, to develop ethical guidelines for hospice workers nationwide on when to report suspicions of assisted suicide. "Hospice staff," Casarett added, "need clear guidance about their ethical and legal obligations when they suspect that a family member has hastened a patient's death." Reporting requirements are

fraught with risk. "Anything that requires reporting, if you overdo it, there's harm," said Pope, who teaches at Hamline University in Minnesota and publishes a blog on futility care. The two note that more than 1.6 million people use hospice every year – a number expected to increase with growth of the elderly population and trends in increased hospice utilization. They hope to publish their findings in medical journals later this year. http://www.philly.com/philly/news/nation_wor/ld/20140305_Guidelines_will_help_end-of-life_oversight.html

Specialist Publications

'What are the consequences of disregarding a "do not resuscitate directive" in the U.S.?' (p.13), in *Medicine & Law*.

Noted in Media Watch, 11 November 2013, #331 (p.3):

- PENNSYLVANIA | *The Morning Call* (Allentown) – 5 November 2013 – **'Pottsville assisted suicide case could affect state end-of-life care laws.'** There's a question that continues to surface in the case of Barbara Mancini, a Philadelphia nurse charged with assisted suicide for giving morphine to her 93-year-old terminally ill father: Why is the Pennsylvania attorney general's office investing its resources to see this case through? <http://www.mcall.com/health/mc-barbara-mancini-assisted-suicide-1105-20131104.0.49266.story>

The town where everyone talks about death

WISCONSIN | National Public Radio – 5 March 2014 – In this community [of La Crosse], talking about death is a comfortable conversation – neighbors gossip about who on the block hasn't filled out their advance directive. It's become such a comfortable conversation, basically because of ... Bud Hammes ... a medical ethicist at a local hospital called Gundersen Health System.¹ For years, he was called when someone's dad had a stroke, was in a coma, on machines. Bud would sit down with the family and try to help them figure out what to do next. And every time, he says, the discussion was excruciating. "The moral distress that these families were suffering was palpable," he says. Most of the time, Bud says, they'd be talking about a patient who had been sick for years. Why not have that conversation earlier? So Bud started training nurses to ask people ahead of time, would you like to fill out an advanced directive. It took a while but the idea caught on. Nurses started asking patients questions like: If you reach a point where treatments will extend your life by a few months and side effects are pretty serious, would you want doctors to stop, or continue to do all that could be done? And a lot of patients said: Stop. And stopping, of course, is less expensive than continuing treatment. In fact, La Crosse, Wisconsin, spends less on health care for patients at the end of life than any other place in the country, according to the Dartmouth Health Atlas.² <http://www.npr.org/blogs/money/2014/03/05/286126451/living-wills-are-the-talk-of-the-town-in-la-crosse-wis>

Cont.

1. Respecting Choices: Advances Care Planning, Gundersen Health System, La Crosse, Wisconsin: <http://www.gundersenhealth.org/respecting-choices>
2. *Tracking Improvement in the Care of Chronically Ill Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life*, June 2013. [Noted in Media Watch, 17 June 2013, #310 (p.4)] http://www.dartmouthatlas.org/downloads/reports/EOL_brief_061213.pdf

Of related interest:

- KENTUCKY | *The Lane Report* (Lexington) – 7 March 2014 – '**End-of-life care bill heads to Senate.**' An end-of-life order known as "medical order for scope of treatment" would be allowed in Kentucky under a bill that passed the Kentucky House on Thursday on an 86-7 vote. Medical orders for scope of treatment spell out a patient's wishes for their end-of-life care. Unlike advance directives, the orders are considered to be physician's orders and are signed by both the patient or patient's legal surrogate, and the patient's physician. <http://www.lanereport.com/30142/2014/03/end-of-life-care-bill-heads-to-senate/>

Palliative chemo can make it more likely you'll die in the ICU

NATIONAL PUBLIC RADIO | Online – 4 March 2014 – Cancer patients who get chemotherapy in the last months of their lives are more likely to die in the intensive care unit, rather than where they wish, a study finds. With more than half of all people with incurable cancer getting palliative chemotherapy in the months before they die, many people could be suffering more than needed. <http://www.npr.org/blogs/health/2014/03/04/285762401/palliative-chemo-can-make-it-more-likely-youll-die-in-the-icu>

N.B. Scroll down to [Specialist Publications](#) and 'Chemotherapy near the end of life' (p.10) for editorial comment on the study, published in the *British Medical Journal*, and for a link to the published research.

[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.

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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.

The challenge of addressing end-of-life care under the current health care model

OHIO | *Crain's Cleveland Business* – 4 March 2014 – A large percentage of total health care spending is devoted to caring for people during their last year of life. This presents a major challenge for anyone trying to regulate or manage our health care system. Just how significant is the cost for what is called end-of-life health care? Consider the following statistics: in an article in *Forbes* back in 2004, it was documented that 30% of all Medicare expenditures are attributed to the 5% of beneficiaries that die each year, with one-third of that cost occurring in the last month of life; a study published in the *Journal of the American Medical Association* found that, between 2000 and 2009, treatment in intensive care units in the last month of life increased from 24% to 29%; the Medicare News Group reported that in 2011, Medicare spending reached nearly \$554 billion, which amounted to 21% of the total spent on U.S. health care in that year. Of that amount, Medicare spent 28%, or \$170 billion, on patients' last six months of life. And when policymakers attempt to address the issue and give thought to any type of pulling back or capping what can or should be spent on someone who is already dying, they are met with chants of death panels. The important question is this: How do you balance the desire to do everything possible to sustain the life of a loved one when there is little that can be done beyond palliative care? And who should have the authority to make those decisions when the care is most often paid for by a third party? <http://www.crainscleveland.com/article/2014/0304/BLOGS05/140309965#>

Of related interest:

- WASHINGTON DC | *The Washington Post* – 6 March 2014 – **'Health & Human Services report, inspection techniques may improve care of nursing homes...'** Federal efforts to strengthen inspections of the nation's nursing homes are gaining momentum after a government probe uncovered instances of sub-standard care. An estimated one-third of residents suffered harm because of sub-standard care and the chances of nursing home inspectors discovering these "adverse events" are "slim to none." http://www.washingtonpost.com/politics/hhs-report-inspection-techniques-may-improve-care-of-nursing-homes-officials-say/2014/03/06/20168184-a57f-11e3-84d4-e59b1709222c_story.html
- *THE WALL STREET JOURNAL* | Online – 3 March 2014 – **'How can we reduce end-of-life health-care costs?'** Balancing cost, care and quality of life near death remains a puzzle for policy makers, practitioners, and of course, patients and their families. [Experts comment.] <http://online.wsj.com/news/articles/SB10001424052702304709904579411083208419794>

Specialist Publications

'What consumers want to know about quality when choosing a hospice provider' (p.8), in *American Journal of Hospice & Palliative Medicine*.

Pitfalls seen in a turn to privately run long-term care

THE NEW YORK TIMES | Online – 6 March 2014 – Even as public attention is focused on the Affordable Care Act, another health care overhaul is underway in many states: an ambitious effort to restrain the ballooning Medicaid cost of long-term care as people live longer and survive more disabling conditions. At least 26 states, including California, Florida, Illinois and New York, are rolling out mandatory programs that put billions of public dollars into privately managed long-term care plans, in hopes of keeping people in their homes longer, and expanding alternatives to nursing homes. But a closer look at Tennessee, widely cited as a model, reveals hidden pitfalls as the system of caring for the frail comes under the twin pressures of cost containment and profit motive. In many cases, care was denied after needs grew costlier – including care people would have received under the old system. http://www.nytimes.com/2014/03/07/nyregion/pitfalls-seen-in-tennessees-turn-to-privately-run-long-term-care.html?hp&_r=0

Lifesaving implants complicate end-of-life care

MASSACHUSETTS | *The Boston Globe* – 3 March 2014 – More than a decade has passed, but Nathan Goldstein, then a medical resident at Mount Sinai Hospital in New York City, still remembers it clearly. A man with terminal lung cancer had planned to die at home with hospice care. Instead, the man was lying on a stretcher in the busy emergency room. Every few minutes, his heart received a shock from his internal defibrillator, preventing his heart from stopping. The implantable cardioverter defibrillator ... can be a lifesaving device when its charge of electricity jolts the heart out of a potentially lethal rhythm. But when someone is dying from an irreversible disease like cancer, the defibrillator's shocks to a failing heart might only serve to postpone death. Ultimately, with the family's consent, Goldstein and his colleagues deactivated the patient's defibrillator. The shocks stopped. And the patient died, not at home the way he and his family had planned, but in the hospital's ER. With more than 100,000 defibrillators and at least twice as many pacemakers implanted in aging patients in the U.S. each year, what to do with these devices in terminally ill patients is becoming a growing issue. Professional societies have issued calls for physicians to address with patients the issue of when to deactivate a defibrillator or pacemaker – implanted devices that can regularize a too-fast or too-slow heartbeat. However, a recent study found that nearly one-third of patients with defibrillators were still receiving shocks in the last 24 hours of their lives.¹ Half of patients with a do-not-resuscitate order still had their defibrillators turned on in the final hour before death. <http://www.bostonglobe.com/lifestyle/health-wellness/2014/03/03/lifesaving-implants-can-complicate-end-of-life-care/T6nNPacKniAk01ON1FkcRM/story.html>

1. 'Features and outcomes of patients who underwent cardiac device deactivation,' *JAMA Internal Medicine*, 2014;174(1):80-85. [Noted in Media Watch, 3 February 2014, #343 (p.2)] <https://archinte.jamanetwork.com/article.aspx?articleid=1783304>

Noted in Media Watch, 27 February 2012, #242 (p.13):

- *THEORETICAL MEDICINE & BIOETHICS*, 2012;33(6):421-433. '**Pacemaker deactivation: Withdrawal of support or active ending of life?**' Traditional medical ethics is presently taken by many to sanction pacemaker deactivation when such deactivation honors the patient's right to refuse treatment. <http://link.springer.com/article/10.1007/s11017-012-9213-5>

Differences in care at for-profit hospices

THE NEW YORK TIMES | Online – 3 March 2014 – People who pay attention to hospice care, so often a godsend for the dying and their families, have noticed and wondered about two trends in recent years: 1) What began as a grass-roots movement to improve end-of-life care is becoming a business. In 1990, only 5% of hospices were for-profit operations; by last year, they dominated the industry, representing 63% of hospices; 2) We've also seen that hospice patients are increasingly likely to be "disenrolled" before they die. Once, this was a rare event; the greater problem was that patients waited until the eleventh hour to enroll, subjecting themselves and their families to unnecessary stress and suffering. Now, about 20% of hospice patients are discharged alive, the Medicare Payment Advisory Commission has found. Some may have moved, or changed their minds about treatment, but the National Hospice & Palliative Care Organization said its surveys show that hospices, not patients, initiate a great majority of discharges. In other words, patients are getting bounced as corporate bottom lines have come to matter more. Are these two developments connected? We've had our suspicions – but now we have data. A study published recently¹ ... has found that for-profit hospices have significantly higher disenrollment rates than non-profits, among other disparities. http://newoldage.blogs.nytimes.com/2014/03/03/differences-in-care-at-for-profit-hospices/?_php=true&_type=blogs&_r=0

1. 'National hospice survey results: For-profit status, community engagement, and service,' *JAMA Internal Medicine*, 24 February 2014. [Noted in Media Watch, 3 March 2014, #347 (p.9)] <https://archinte.jamanetwork.com/article.aspx?articleid=1832198>

No matter the species

For pets' sake: Palliative care, end-of-life options also important to consider for pets

VIRGINIA | *The Daily Progress* (Charlottesville) – 3 March 2014 – Palliative care and hospice are important parts of end-of-life care in human medicine, and are a growing area of interest in veterinary medicine. These types of care can be described as treatment meant to give support and improve quality of life so that an individual may live as fully and comfortably as possible, despite incurable disease. These philosophies provide guidance as we define hospice in veterinary medicine and extend this type of care to our aged and terminally ill pets. When is palliative care appropriate for a pet? Truly, much of what we do in veterinary medicine is already "palliative care." http://www.dailyprogress.com/lifestyles/for-pets-sake-palliative-care-end-of-life-options-also/article_79e5da76-9f2a-11e3-92de-0017a43b2370.html

Of related interest:

- *THE CANADIAN JEWISH NEWS* | Online – 4 March 2014 – **'Mobile vet provides services for aging and ill pets.'** Palliative and end-of-life home care are growing and accepted parts of modern medicine for people. But Toronto veterinarian Faith Banks is one of the few in her profession offering mobile palliative and hospice-like care for aging and terminally ill pets. <http://www.cjnews.com/index.php?q=node/122716>

Noted in Media Watch, 16 December 2013, #336 (p.4):

- MICHIGAN | *DVM360 Magazine* – 3 December 2013 – **'Veterinarians launch hospice and palliative care organization.'** With the exponential expansion of palliative and hospice care in the past few years, it is emerging as a distinct discipline of veterinary medicine. <http://veterinarynews.dvm360.com/dvm/Veterinary+news/Veterinarians-launch-hospice-and-palliative-care-o/ArticleStandard/Article/detail/830029?contextCategoryId=378>

N.B. Veterinary Society for Hospice % Palliative Care website: <http://cvm.msu.edu/hospital/services/veterinary-hospice-care/the-veterinary-society-for-hospice-and-palliative-care>. Additional articles that draw a parallel between end-of-life care for animals and humans are noted in Media Watch, 2 December 2013, #334 (p.4).

Hospice Without Borders

Volunteers start non-profit hospice care for homeless

STATE OF WASHINGTON | *Thurston Talk* – 2 March 2014 – Knowing a family member is only days away from death can be a painful experience. Many want to spend those last moments with their loved ones while others struggle with the idea of saying goodbye. This is an even more difficult experience for those who are in need of hospice care, but do not have a means of receiving it. That's where Hospice Without Borders has stepped in with a new, entirely volunteer hospice care center in East Olympia. "Amahoro House means peace," explains Volunteer Coordinator for Hospice Without Borders, Debe Eden. "Our goal is to bring peace to

our guests." The hospice is planning to open this spring and offer care to homeless community members in need of around the clock care. <http://www.thurstontalk.com/2014/03/02/volunteers-start-non-profit-hospice-care-homeless/>

Specialist Publications

'Reaching out to Ray: Delivering palliative care services to a homeless person in Melbourne, Australia' (p.12), in *International Journal of Palliative Nursing*.

N.B. Hospice Without Borders website: <http://www.hospicewithoutborders.com/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CONNECTICUT | Quinnipiac University (Hamden) – 6 March 2014 – **'Connecticut voters back suicide bill almost 2-1, Quinnipiac University poll finds.'** Connecticut voters support 61-32%, with support from all age, party and gender groups, allowing doctors to legally prescribe lethal drugs to help terminally ill patients end their own lives, an independent Quinnipiac University poll finds. Support is 63-31% among men, 58-33% among women, 51-42% among Republicans, 66-28% among Democrats and 63-31% among independent voters. Voters 18 to 29 years old support it 63-28%, with support at 54-37% among voters over 65. Voters are closely divided on whether they would ask a doctor to help them take their own life, as 39% say no in all cases, while 33% say they would if they were terminally ill, and another 12% would if they were terminally ill and in pain. <http://www.quinnipiac.edu/institutes-and-centers/polling-institute/connecticut/release-detail?ReleaseID=2016>
- NEW HAMPSHIRE UNION LEADER | Online – 6 March 2014 – **""Death with Dignity Act finds little support in New Hampshire House""** The House ... soundly rejected legislation that would have allowed a terminally ill patient to seek a lethal prescription from cooperating physicians. Under House Bill 1325, the "Death with Dignity Act," the patient must have received a prognosis of six months or less to live by two physicians. The vote against the bill was 219-66. But the House approved establishing a new seven-member committee to study "end-of-life" decisions and the state's medical directive law. The vote to pass House Bill 1226 was 162-126. <http://www.unionleader.com/article/20140306/NEWS0621/140309414>

International

Home care in Australia

Concerns of lonely seniors in home care push

AUSTRALIA (Victoria) | *Australian Ageing Agenda* – 5 March 2014 – Policy reform to support older people to live at home for as long as possible may lead to higher levels of social isolation and associated mental health issues, a new report has warned.¹ The report from seniors advocacy group COTA [Council on the Ageing] Victoria said while it fully endorsed the policy shift, there were also potential risks that had to be managed. COTA Victoria said unless community services were properly resourced and supported by investment in age-friendly housing and accessible public transport, some older people were at risk of becoming even more isolated. <http://www.australianageingagenda.com.au/2014/03/05/report-highlights-risks-home-care/>

1. 'Social isolation: Its impact on the mental health and wellbeing of older Victorians.' Council on the Ageing Victoria Working Paper #1, February 2014. http://www.cotavic.org.au/wp-content/uploads/2014/02/Working-Paper_Social-Isolation.pdf

Brain zap can "wake" nearly-comatose patients

BELGIUM | ABC News (U.S.) – 3 March 2014 – Researchers in Belgium have found that mild electrical stimulation can temporarily rouse nearly-comatose patients.¹ During the study the patients, all of whom were either minimally conscious or in [a] vegetative state, underwent mild electrical stimulation for twenty minutes at a time. Researchers found that 15 of the minimally conscious patients responded to the stimulation by becoming more responsive and two were even able to communicate non-verbally with researchers. <http://abcnews.go.com/Health/brain-zap-wake-comatose-patients/story?id=22722089>

1. 'tDCS in patients with disorders of consciousness: Sham-controlled randomized double-blind study,' *Neurology*, 26 February 2014. <http://www.neurology.org/content/early/2014/02/26/WNL.000000000000260.abstract?sid=b1f7de5f-ff33-4b8c-af4e-204499523301>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Daily Telegraph* – 7 March 2014 – **'Recession has heightened euthanasia "danger" to disabled and elderly, claims peer.'** Baroness Campbell of Surbiton, who suffers from a degenerative illness, issued an impassioned plea to the House of Lords against moves to further relax Britain's laws on assisted suicide. She argued part of the legacy of the long economic downturn and austerity programme had been a serious hardening of attitudes towards vulnerable members of society. <http://www.telegraph.co.uk/news/politics/10681076/Recession-has-heightened-euthanasia-danger-to-disabled-and-elderly-claims-peer.html>

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

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

What consumers want to know about quality when choosing a hospice provider

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 4 March 2014 – Despite the availability of quality measures and widespread usage of hospice, hospice quality data are rarely available to consumers. Moreover, little is known about how consumers prioritize extant measures. Study participants placed top priority on measures related to pain and symptom management. Relative to consumers with hospice experience, consumers without previous experience tended to place less value on spiritual support for patients and caregivers, emotional support for caregivers and after-hours availability. The National Quality Forum-approved measures resonate well with consumers. Consumers appear to be ready for access to data on the quality of hospice providers. <http://ajh.sagepub.com/content/early/2014/02/27/1049909114524475.abstract>

Of related interest:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 March 2014 – **'Not quite seamless: Transitions between home and inpatient hospice.'** Transitions ... centered on three processes [identified in this study]: 1) developing a plan for future needs; 2) identifying triggers that signaled increased needs for care; 3) and, navigating through phases of increased care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0359>

Service user perspectives on palliative care education for health and social care professionals supporting people with learning disabilities

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 4 March 2014 – Evidence from European and American studies indicates limited referrals of people with learning (intellectual) disabilities to palliative care services. Although professionals' perceptions of their training needs in this area have been studied, the perceptions of people with learning disabilities and family carers are not known. This study shows that people with learning disabilities can have conversations about death and dying, and their preferred end-of-life care, but require information that they can understand. <http://spcare.bmj.com/content/early/2014/03/04/bmjspcare-2013-000615.abstract>

Noted in Media Watch, 11 November 2013, #331 (p.15):

- *PERSPECTIVES ON GERONTOLOGY*, 2013;18(3):380-387. **'Supporting adults with intellectual and developmental disabilities and communication disorders to express end-of-life wishes.'** This article addresses end-of-life communication issues faced by adults with intellectual and developmental disabilities, their caregivers, and medical professionals. <http://div15perspectives.asha.org/content/18/3/80.abstract>

Cont.

Noted in Media Watch, 22 April 2013, #302 (p.9):

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES*, 2013;26(3):215-230. **'The experiences of staff in dealing with matters of dying and death in services for people with intellectual disabilities.'** This paper looks at the experiences of staff in dealing with issues of death and dying. <http://onlinelibrary.wiley.com/doi/10.1111/jar.12024/abstract>

N.B. This issue of the journal focuses on dying and death, and people living with intellectual disabilities. Contents page: <http://onlinelibrary.wiley.com/doi/10.1111/jar.2013.26.issue-3/issuetoc>

Parents and end-of-life decision-making for their child: Roles and responsibilities

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 4 March 2014 – Whether parents want to be and should be the decision-maker for their child in end-of-life matters are contested clinical and ethical questions. This study unequivocally supports parents' desire to fulfil the end-of-life decision-making role. It provides a nuanced understanding of parents' roles and contributes evidence for the ethical position that parents should be the end-of-life decision-makers for their child, unless not in the child's best interests. On the whole, parents want this role and can manage its consequences. Indeed, not being the end-of-life decision-maker could be detrimental to parents' well-being. <http://spcare.bmj.com/content/early/2014/03/04/bmjspcare-2013-000558.abstract>

What do physicians think about paediatric palliative care? A survey in Singapore

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2014;21(2):93-97. While adult palliative care has been gaining wider acceptance, public and professional awareness of the benefits of paediatric palliative care is still lacking. This study revealed significant concerns that could be barriers to early and appropriate referral.

N.B. Access requires a subscription. Contents page: http://www.haywardpublishing.co.uk/_year_search_revew.aspx?JID=4&Year=2014&Edition=504

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

- *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/>

Cont. next page



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>

- *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/archdischild-2013-304249.abstract>
- *PROGRESS IN PALLIATIVE CARE* | Online – 15 October 2012 – **'The child's voice in pediatric palliative and end-of-life care.'** The absence of the child's voice in palliative and end-of-life care jeopardizes best care efforts. [Noted in Media Watch, 22 October 2012, #276 (p.9)] <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000035>

Of related interest:

- *RHODE ISLAND MEDICAL JOURNAL*, 2014;97(3):26-30. **'Spirituality and coping with chronic disease in pediatrics.'** The existing literature, though sparse, reveals that children have a rich and complex spiritual life; one which often goes beyond religiosity to examine purpose in the context of illness. <http://www.ncbi.nlm.nih.gov/pubmed/24596927>

Chemotherapy near the end of life

BRITISH MEDICAL JOURNAL | Online – 5 March 2014 – Even as cancer treatments become more effective, we can still wonder about the symbolic meaning behind decisions to pursue chemotherapy near the end of life. Although most patients with metastatic cancer choose to receive palliative chemotherapy, evidence suggests most do not clearly understand its intent.¹ In decision making about chemotherapy, doctors are supposed to describe, and patients are supposed to understand, the direct outcomes of the proposed treatment (for example, clinical response rates and side effects). However, the broader implications of such decisions can be just as important. In the linked paper by Wright and colleagues,² choosing palliative chemotherapy was associated with a whole set of outcomes that may not have been known, expected, or discussed by patients, their family caregivers, and their oncologists. <http://www.bmj.com/content/348/bmj.g1529>

1. 'Patients' expectations about effects of chemotherapy for advanced cancer,' *New England Journal of Medicine*, 2012;367(17):1616-1625. [Noted in Media Watch, 29 October 2012, #277 (p.2)] <http://www.nejm.org/doi/full/10.1056/NEJMoa1204410>
2. 'Associations between palliative chemotherapy and adult cancer patients' end of life care and place of death: prospective cohort study,' *British Medical Journal*, 4 March 2014. http://www.bmj.com/content/348/bmj.g1219?ikey=7ed3355f280bcee188aa1fcf5389d195f2b8946b&keytype2=tf_ipsecsha&linkType=ABST&journalCode=bmj&resid=348/mar04_4/g1219&atom=/bmj/348/bmj.g1529.atom

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

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

[Media Watch Online](#)

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

Virtual mourning and memory construction on Facebook: Here are the terms of use

BULLETIN OF SCIENCE TECHNOLOGY SOCIETY | Online – Accessed 5 March 2014 – This article investigates the online information practices of persons grieving and mourning via Facebook. It examines how, or whether, these practices and Facebook's terms of use policies have implications for the bereaved and/or the memory of the deceased. To explore these questions, the authors compared traditional publicly recorded asynchronous modes of grieving (i.e., obituaries) with Facebook's asynchronous features (i.e., pages, photos, messages, profiles, comments). Additionally, by applying observational techniques to Facebook memorial pages and Facebook profiles, conducting a survey, and interviewing respondents as a follow-up to the survey, we examined the benefits of and issues surrounding online information sharing via Facebook when coping with the loss of another. The authors found that the immediacy of publishing comments, messages, wall posts, and photos provides Facebook mourners with a quick outlet for their emotions and a means of timely group support; however, these actions directly affect the online curation of the deceased's self and memory and also create an environment of competition among mourners. <http://bst.sagepub.com/content/early/2013/12/18/0270467613516753.abstract>

Noted in Media Watch, 5 March 2012, #243 (p.11):

- *OMEGA – JOURNAL OF DEATH & DYING*, 2012;64(4):275-302. **'Does the Internet change how we die and mourn?'** The article outlines issues the Internet presents to death studies. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue.1.6:jurnal.1.255:linkingpublicationresults.1:300329.1>

Awareness of the European Association for Palliative Care recommendations on palliative sedation: A web-based survey

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2014;21(2):81-85. In 2009, the European Association for Palliative Care (EAPC) published a recommended framework on the use of sedation in palliative care.¹ In 2012, a web-based survey explored EAPC members' awareness of these recommendations. A total of 99 members – 76 individual members and 23 collective members (out of 51) – from 37 countries responded to the survey. A large majority of respondents were aware of the EAPC's recommendations. The results of the survey support the idea that providing guidance to its members is an important task for the EAPC.

1. 'European Association for Palliative Care recommended framework for the use of sedation in palliative care,' 2009. <http://www.eapcnet.eu/LinkClick.aspx?fileticket=RKDokneiDjc%3d&tabid=38>

N.B. Access requires a subscription. Contents page:

http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2014&Edition=504

Of related interest:

- *JOURNAL OF MEDICAL ETHICS* | Online – 4 March 2014 – **'Dutch physicians on the role of the family in continuous sedation.'** Dutch physicians viewed the role of family in continuous sedation as important and potentially difficult. Difficulties may rise especially during the final stages when the patient is no longer conscious and family members are waiting for death to come. Disagreement may arise between physician and family, concerning the dignity of the dying process or the question whether the sedated patient is suffering or not. <http://jme.bmj.com/content/early/2014/03/04/medethics-2013-101624.abstract>

N.B. Representative sample of articles on palliative sedation noted in past issues of Media Watch is listed in the 10 February 2014 (#344) issue of the weekly report (p.11).

Reaching out to Ray: Delivering palliative care services to a homeless person in Melbourne, Australia

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2014;20(2):83-88. This paper describes a quality-improvement project by a community-based palliative care service in Melbourne, Australia, to understand homeless people's palliative care needs and the challenges that workers face. The results [of interviews with workers in hospital and community-based settings] were used to initiate discussion about how policy and protocols for the community-based palliative care service might serve this population more effectively. Findings confirmed homeless people have complex psychosocial and medical needs. They may be periodically uncontactable or living in unsafe settings, experience isolation from social support networks and have issues of compliance with treatment protocols exacerbated by mental health problems and/or substance abuse. Service providers had particular challenges in meeting the palliative care needs of homeless people. A flexible, compassionate, and coordinated response is required, and more work is needed to explore how the needs of this particular group can be met. http://www.internurse.com/cgi-bin/go.pl/library/article.cgi?uid=103388;article=IJPN_20_2_83_88;format=pdf

Noted in Media Watch, 3 February 2014, #343 (p.4):

- IRELAND | *The Irish Times* (Dublin) – 30 January 2014 – '**Need for end-of-life care for older homeless, report finds.**' Provision should be made within the health service for end-of-life care for older homeless people, a new Irish study recommends. 'Homelessness, Ageing & Dying,' commissioned by the Simon Communities of Ireland, found many older homeless people had a fear of dying on the streets or of dying alone and their body not being found for weeks. <http://www.irishtimes.com/news/ireland/irish-news/need-for-end-of-life-care-for-older-homeless-report-finds-1.1673728>

N.B. Representative sample of articles on end-of-life care for homeless people noted in past issues of Media Watch are listed in this issue of the weekly report.

Effectiveness of eHealth interventions and information needs in palliative care: A systematic literature review

JOURNAL OF MEDICAL INTERNET RESEARCH, 2014;16(3):e72. The authors found no randomized controlled trial studying the effects of eHealth interventions in palliative care. Studies tended to be observational, non-controlled, and a few quasi-experimental studies. Overall there was great heterogeneity in the types of interventions and outcome assessments; some studies reported some improvement on quality of care, documentation effort, cost, and communications. The most frequently reported information need concerned pain management. There is limited evidence around the effectiveness of eHealth interventions for palliative care patients, caregivers, and health care professionals. <http://www.jmir.org/2014/3/e72/>

When open-ended questions don't work: The role of palliative paternalism in difficult medical decisions

JOURNAL OF PALLIATIVE MEDICINE | Online – 3 March 2014 – Autonomy is the current gold standard approach to patient communication and has grown to the point that patient preference dictates care, even when their choices are not possible or are medically non-beneficial. Furthermore, the authors have observed a trend among physicians to avoid making difficult medical decisions by hiding behind a shield of patient autonomy. Paternalism, characterized as the antithesis of autonomy, is widely dismissed as having any role in medicine. The authors disagree and believe that paternalism still has an important role in medical decision making. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0408>

Cont.

Noted in Media Watch, 5 September 2011, #217 (p.8):

- *THE HASTINGS REPORT*, 2011;41(5):3. **'Patient autonomy and the twenty-first century physician.'** Daniel Groll suggests new ways to understand old tensions between autonomy and paternalism.¹ <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5492>
 1. 'What health care providers know: A taxonomy of clinical disagreement,' *The Hastings Report*, 2011;41(5):27-36. Some assume that respecting patient autonomy means clinicians should refrain from expressing opinions about what's in a patient's best interests...
<http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5503>

Promoting palliative care worldwide through international nursing education

JOURNAL OF TRANSCULTURAL NURSING | Online – 4 March 2014 – Though issues related to culture and language may vary, the one commonality that crosses all nations is that its people die. In general, societies seek to provide the best care they are trained to give. Many have few resources to provide this care well. Traditions of the past influence norms and dictate policies and procedures of the present. Since its inception in 2000, the End-of-Life Nursing Education Consortium Project has provided palliative care education to nurses and other members of the interdisciplinary team in six of the seven continents. This article describes the efforts of this project to improve education around the globe, with the goal of providing excellent, compassionate palliative care, irrespective of location, financial status, political views, religion, race, and/or ethnicity. <http://tcn.sagepub.com/content/early/2014/03/03/1043659614523993.abstract>

Of related interest:

- *MEDICAL TEACHER* | Online – 4 March 2014 – **'Developing learning outcomes for medical students and foundation doctors in palliative care: A national consensus-seeking initiative in Scotland.'** Consensus learning outcomes for undergraduate palliative care were agreed by our mixed group of clinician educators over a number of months. There were many secondary gains from this process, including the pooling of educational resources and best practice, and the provision of peer support for those struggling to establish curriculum time for palliative care. <http://informahealthcare.com/doi/abs/10.3109/0142159X.2014.889289>

What are the consequences of disregarding a "do not resuscitate directive" in the U.S.?

MEDICINE & LAW, 2013;32(4):441-458. Does a valid cause of action exist against a health care provider who intentionally disregards a "do-not resuscitate order," prolonging a patient's life? Wrongful prolongation of life has not gained traction in the U.S. Although the issue has garnered media attention and has raised awareness of advanced directives, physicians still may disregard a patient's last wishes for fear of legal reprisal or due to lack of communication. This article examines key cases and explains the differences between living wills, advanced directives and proxies. Claims have been advanced under theories of battery, Constitutional violations, breach of contract, infliction of emotional distress, and negligence, but no cause of action has allowed monetary damages. Courts maintain that it is not their place to judge an impaired life as being less valuable than no life. A state-by-state analysis of legislation concerning advanced directives follows along with a discussion of the Patient Self-Determination Act [1990]. http://www.researchgate.net/publication/260268504_What_are_the_consequences_of_disregarding_a_do_not_resuscitate_directive_in_the_United_States

Of related interest:

- *JOURNAL OF PATIENT SAFETY* | Online – 27 February 2014 – **'Nationwide survey of medical students' understanding of living wills and DNR orders.'** Data indicate that the majority of survey respondents failed to understand the key elements of a living will; adding a code status designation improved correct responses with the exception of the term DNR. Misunderstanding of advance directives is a nationwide problem and jeopardizes patient safety. http://journals.lww.com/journalpatientsafety/Abstract/publishahead/TRIAD_IV_Nationwide_Survey_of_Medical_Students_.99782.aspx

How do patients respond to end-of-life status?

NURSING TIMES | Online – 7 March 2014 – Despite indications that [study] participants might be nearing the end of their lives, most were unaware of their prognosis and showed little insight into what they could expect from the trajectory of their disease. Patients can be reluctant to gain knowledge that requires them to face the imminence of death. This can create tensions for nurses about how they relate to and communicate with patients facing incurable illnesses. To ensure timely access to palliative care, new and innovative ways of delivering palliative care are needed, which do not rely on the ideologically based assumption that awareness can and should be encouraged in all cases. <http://www.nursingtimes.net/home/clinical-zones/end-of-life-care/how-do-patients-respond-toend-of-life-status/5068714.article?blocktitle=This-Week's-Practice&contentID=4386>

Exploring occupation roles of hospice family caregivers from Māori, Chinese and Tongan ethnic backgrounds living in New Zealand

OCCUPATIONAL THERAPY INTERNATIONAL | Online – 28 February 2014 – In each of their homes, informants [i.e., study participants] were asked to discuss what it was like caring for their dying family member. The occupational themes resulting from these interviews were food preparation, spirituality and family gathering. Therapists need to be aware of the differences in how people care for family members within their ethnicity. Implications are that occupational therapists can help families identify activities important to them within the main occupational themes: different types of foods and their preparations, various ways to express spirituality and how families gather together

members of their extended family. <http://onlinelibrary.wiley.com/doi/10.1002/oti.1367/abstract;jsessionid=F7B65696E658326AA5B1D3FCB0E34769.f04t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Extract from *Occupational Therapy International* article

Clinicians need to take on the role of a "not-knowing" but curious health-care provider in order to meet the needs of caregivers.

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(2):61-65. **'Assisted suicide in Switzerland: Where have we come from and where are we going?'** In Switzerland, while assisted suicide is not explicitly permitted by the law, suicide assistance has been decriminalised for nearly 100 years if the person seeking assistance is competent and if the person assisting them is not motivated by self-interest. Right-to-die organisations such as Exit and Dignitas provide aid in dying. Some of them also help non-residents, which has led to the controversial (and ill-named) phenomenon of "suicide tourism." There have been attempts to regulate or ban assisted suicide. In 2011, the Swiss Federal Council decided not to change the law but to increase measures to prevent suicides and promote palliative care. A national palliative care strategy has been put in place.¹ Physician-assisted suicide is controversial among the medical professions, including palliative care professionals. The Swiss Academy of Medical Sciences is conducting a survey on the issue.

1. Palliative Care Strategy, Switzerland, website: <http://www.bag.admin.ch/themen/gesundheitspolitik/13764/index.html?lang=en>

N.B. Access requires a subscription. Contents page: http://www.haywardpublishing.co.uk/year_search_review.aspx?JID=4&Year=2014&Edition=504

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/3/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>

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