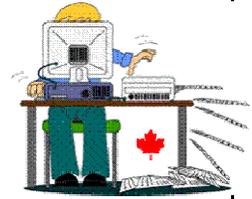


Media Watch...

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.

8 December 2014 Edition | Issue #387



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Compiled & Annotated by Barry R. Ashpole

Continuity of care: Scroll down to [Specialist Publications](#) and 'The use of palliative care to promote autonomy in decision making' (p.11), in *Clinical Journal of Oncology Nursing*.

Canada

Don't make employees choose between their job and providing end-of-life care to a loved one

THE FINANCIAL POST | Online – 1 December 2014 – One obvious and unfortunate consequence of baby boomers getting older is an increased death rate. The oldest are now just two years shy of their eighth decade, and by 2020 Canada's death rate is expected to rise 20% to 300,000 annually. For employers this will mean greater employee demand for compassionate care leave, as more than half of palliative care patients are cared for primarily by spouses, partners or children. Job protection for those taking time off from work to provide end-of-life care for loved ones is already guaranteed by both federal and provincial governments. But many companies are going a step further, implementing their own compassionate care leave policies to provide greater comfort and accommodation to employees. A recent survey¹ ... found 59% of 692 organizations polled had formal compassionate care leave policies that recog-

nize and accommodate employees' family and dependent care responsibilities for providing end-of-life care to loved ones. <http://business.financialpost.com/2014/12/01/dont-make-employees-choose-between-their-job-and-providing-end-of-life-care-to-a-loved-one/>

Specialist Publications

'Societal costs of home and hospital end-of-life care for palliative care patients in Ontario, Canada' (p.11), in *Health & Social Care in the Community*.

'Task shifting in the provision of home and social care in Ontario, Canada: Implications for quality of care' (p.12), in *Health & Social Care in the Community*.

1. 'Compassionate Care Policy,' Research by the Human Resources Professionals Association, in partnership with the Canadian Hospice Palliative Care Association, October 2014. http://www.hrpa.ca/Documents/360/Compassionate_Care_Policy.pdf

Cont.

Noted in Media Watch, 16 June 2014, #362 (p.1):

- CANADIAN HUMAN RIGHTS COMMISSION | Online – 11 June 2014 – '**Balancing work and caregiving obligations: New guide walks you through it.**' The Commission has released its 'Guide to Balancing Work and Caregiving Obligations: Collaborative approaches for a supportive and well-performing workplace.' The guide offers employers and employees practical tips on what to do when an employee's family caregiving and work responsibilities come into conflict. http://www.chrc-ccdp.gc.ca/sites/default/files/a_guide_to_balancing_work.pdf

Do away with the term "do not resuscitate"

THE NATIONAL POST | Online – 1 December 2014 – "Should your heart stop beating while under my care, would you like us to attempt CPR (cardiopulmonary resuscitation)?" It is a question most physicians dread asking, as no matter how the issue is raised, patients and family members react at first with shock, aghast that this is even a question at all. Swayed by Hollywood's depiction of cardiac arrests, where 75% of fictional resuscitation attempts are successful and uncomplicated, the initial answer for most patients as to whether to attempt CPR if their heart stops beating in a hospital is an automatic "yes." Unfortunately, the statistics are far more grim, and the decision far more difficult. CPR performed on patients who are already in hospital carries a survival rate of approximately 15%, while CPR performed in nursing homes achieves only a 2% survival rate. Survival rates among those with serious illnesses such as cancer (6.7%) and dialysis (2%) are dismal. Due to these stark outcomes, physicians are obligated, when treating patients whose CPR outcomes are

the most bleak, to clarify whether resuscitation in hospital is indeed what these patient and their loved ones want. I make it clear in these discussions CPR is likely to fail, likely to be painful while it is being performed and, if successful, will carry a 50% chance of life-long institutionalization and/or brain damage. <http://fullcomment.nationalpost.com/2014/12/01/brett-belchetz-do-away-with-the-term-do-not-resuscitate/>

Extract from *The National Post* article

In order to deal with the fact that most elderly and severely ill patients opt out of receiving CPR once the risks are explained to them, but are leery about signing DNR forms, we need to change our vocabulary. Instead of asking patients who say no to CPR to sign a form telling us not to care for them, physicians should be asking them to affirm their preference for a natural, dignified passing. Simply put, I believe the term DNR needs to go away, to be replaced with the term AND – Allow Natural Death.

Noted in Media Watch, 5 May 2014, #356 (p.15):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 28 April 2014 – '**A communication training perspective on AND versus DNR directives.**' The term "do not resuscitate" (DNR) is challenging to use in end-of-life discussions because it omits the goals of care. "Allow Natural Death" (AND) has been proposed as a better way of framing this palliative care discussion. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9247509&fulltextType=CR&fileId=S147895151400039X>

Noted in Media Watch, 9 July 2012, #261 (p.11):

- *HEC FORUMS* | Online – 1 July 2012 – '**Allow natural death orders: Legal, ethical, and practical considerations.**' Conversations with patients and families about the Allow-Natural Death (AND) order, along with the standard Do Not Resuscitate (DNR) order during end-of-life decision-making, may create engagement and understanding while promoting care that can be defended using enduring the notions of autonomy, beneficence, and professional duty. <http://www.springerlink.com/content/112grh2277342362/>

N.B. Footnoted in this issue of Media Watch is articles on allow-natural death noted in past issues of the weekly report.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 1 December 2014 – '**Senate bill ensures assisted suicide will be an issue in 2015 federal election.**' Conservative MP Steven Fletcher's wish for a political debate on physician-assisted suicide will be granted. Two senators will bring legislation to the upper chamber virtually ensuring the debate takes place before the 2015 federal election. Many MPs have been reluctant to deal with the question. But if the Senate bill moves fast enough, they may have no choice but to confront it. A bill passed quickly in the Senate would bounce into the House of Commons – and leap ahead of Mr. Fletcher's existing private members' bills, which are currently low on the Commons' order of business and hence unlikely to be debated there before the election. <http://news.nationalpost.com/2014/12/01/senate-bill-ensures-assisted-suicide-will-be-an-issue-in-next-federal-election/>

Noted in Media Watch, 22 September 2014, #376 (p.3):

- MANITOBA | *The Winnipeg Free Press* – 16 September 2014 – '**Fletcher to take suicide bill to Senate: Issue not on Parliament's agenda.**' Physician-assisted suicide will be a reality in Canada no matter what the federal government wants, Manitoba Conservative MP Steven Fletcher said. Fletcher was reacting to comments from Health Minister Rona Ambrose, who said in an interview with CBC assisted suicide is not her priority. <http://www.winnipegfreepress.com/local/fletcher-to-take-suicide-bill-to-senate-275245651.html>

U.S.A.

Finding peace at the end of life

MICHIGAN | *The Lansing State Journal* – 5 December 2014 – Physicians know their patients' diagnoses and prognoses, as well as the potential effectiveness or ineffectiveness of therapies. Patients know how they feel and are aware of their response to treatment. Family members note the effects of illness on their loved one. Physicians should lead the way in the communication. The most important message physicians can give their patients and families is the assurance they will not be abandoned. The patient and family can then focus on peace and comfort while preparing for death. To effectively consider possible therapy options, patients need accurate, appropriate and timely information about the benefits and burdens of possible therapies. They also need to know what might be expected as death approaches. Dying is best faced as a team: patient, family, physician and other health care providers. Each team member has unique responsibilities. The role of the physician is to provide adequate and timely information for making treatment decisions. <http://www.lansingstatejournal.com/story/opinion/contributors/outlook/2014/12/05/dr-james-grant-finding-peace-end-life/19958343/>

Michigan chose better treatment over death

MICHIGAN | *The Lansing State Journal* (OpEd) – 5 December 2014 – We chose not to legalize assisted suicide via a 1998 statewide ballot question ... by a 71% to 29% margin. We recognized that we failed if our solution to suffering was to kill those who suffer. Better alternatives were available. We approved new laws and administrative rules to increase access to hospice care, gave doctors more discretion to aggressively use pain medications, and improved training for palliative care and pain management in the health professions. Both the Michigan Legislature and the blue-ribbon panel it appointed, the Michigan Commission on Death & Dying, identified compelling reasons for choosing the course away from suicide and toward high quality end-of-life care. <http://www.lansingstatejournal.com/story/opinion/contributors/outlook/2014/12/05/ed-rivet-michigan-chose-better-treatment-death/19955045/>

Eldercare "scorecard" rates states in effort to stress Independence

NEW AMERICA MEDIA | Online – 5 December 2014 – The way the medical system talks about aging often gets it all wrong. That's what Bruce Chernof, a physician and head of The SCAN Foundation, based in Long Beach, Calif., wants you to know. "People define themselves by the function they retain, not the function they've lost," he said. That means there's a huge disjoint between the words older Americans use most frequently to describe the kind of care they want in later life (words like "choice," "independence," "dignity") and the most common words doctors rely on ("palliative care," "geriatrics," "advanced directive," "donut hole"). Chernof, who is also the former director of the Los Angeles County Department of Health Services, is on a mission: getting health professionals to think about how to engage people around aging outside of the traditional medical model. In 2014, Chernof's SCAN Foundation and the Commonwealth Fund of New York produced a scorecard on long-term care capacity that was compiled by the American Association of Retired Person's Public Policy Institute.¹ It was the second annual scorecard and ranked states on criteria like affordability and access, choice of setting and provider, quality of life and quality of care, and support for family caregivers. California ranked ninth in the U.S. According to the report that makes it "a leading state in an imperfect system."

<http://newamericamedia.org/2014/12/eldercare-scorecard-rates-states-in-effort-to-stress-independence.php>

1. 'Raising expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers,' Commonwealth Fund, Scan Foundation and American Association of Retired Persons, June 2014. [Noted in Media Watch, 23 June 2014, #363 (p.3)] <http://www.freep.com/assets/freep/pdf/C4221884619.PDF>

Why Vermont has been slow to adopt hospice care

VERMONT | *Seven Days* (Burlington) – 3 December 2014 – Surprisingly, a comparatively small number of Vermonters find physical, emotional and spiritual comfort in hospice settings. Vermont ranked 48th among the states in the rate of hospice utilization...¹ Only New Yorkers and Alaskans were proportionately less likely to choose this different way of dying. Approximately 5,500 people die in Vermont annually, but only 1,763 Vermonters made use of Medicare's hospice benefit in 2011, according to the Centers for Medicare & Medicaid Services. The Visiting Nurse Association of Chittenden & Grand Isle Counties estimates that about 30% of deaths in the state take place in hospice care. At the same time, "the vast majority of Vermonters say they would rather die at home than in a hospital or nursing facility." <http://www.sevendaysvt.com/vermont/packed-prisons-retain-inmates-past-their-release-dates/Content?oid=2481328>

1. *Trends and Variation in End-of-Life Care for Medicare Beneficiaries with Severe Chronic Illness*, A report of the Dartmouth Atlas Project, Dartmouth Institute for Health Policy & Clinical Practice, Hanover, New Hampshire, April 2011. [Noted in Media Watch, 18 April 2011, #197 (p.3)] http://www.dartmouthatlas.org/downloads/reports/EOL_Trend_Report_0411.pdf



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>

How to make your wishes for end-of-life care clear

THE WALL STREET JOURNAL | Online – 30 November 2014 – As acceptance of end-of-life planning grows in the U.S., new concerns are emerging about how well patients and their doctors understand the forms they are signing about the care they want in their final days. In September, the Institute of Medicine's 'Dying in America' report called for a national effort to improve medical and social services for end-of-life care,¹ both to improve quality of life and to help reduce the outsize costs of unwanted care at the end of life. Some health plans are reimbursing doctors who help with advance care planning, and the federal government is weighing doing the same for doctors who talk to Medi-

care patients about options. But while the "death panels" controversy has faded, some experts say there is much education still to be done on advance directives such as living wills and do-not-resuscitate, or DNR, orders. <http://online.wsj.com/articles/how-to-make-your-wishes-for-end-of-life-care-clear-1417408059>

Specialist Publications

'The use of palliative care to promote autonomy in decision making' (p.11), in *Clinical Journal of Oncology Nursing*.

1. 'Dying in America: Improving quality and honoring individual preferences near the end of life,' Institute of Medicine, September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>

International

End-of-life care in Ireland

Only 1 in 3 people who want to die at home do so

IRELAND | *The Irish Times* (Dublin) – 4 December 2014 – Just one out of every three people who would like to do at home actually do so, according to a new report.¹ People's preference to die in their own homes is not being facilitated by the health system ... which finds large disparities in the numbers dying at home in different areas. People in County Donegal are almost twice as likely to die in their own home as those in Dublin, it points out. The figures for all counties are much lower than the 74% of people who told a previous survey they wanted to die at home.² The report calls for health policy to focus more on providing care in the home and community, and makes the case for the

introduction key quality indicators on place of care and death as a way to monitor how well policy is being implemented. <http://www.irishtimes.com/news/health/only-1-in-3-people-who-want-to-die-at-home-do-so-1.2025581>

Specialist Publications

'Dying at home: A qualitative study of family carers' views of support provided by GPs community staff' (p.10), in *British Journal of General Practice*.

1. 'Enabling More People to Die at Home: Making the case for quality indicators as drivers for change on place of care and place of death in Ireland,' The Irish Hospice Foundation, December 2014. <http://hospicefoundation.ie/wp-content/uploads/2014/12/Enabling-More-People-to-Die-at-Home1.pdf>
2. 'Access to Specialist Palliative Care Services and Place of Death in Ireland,' The Irish Hospice Foundation, May 2013. [Noted in Media Watch, 28 October 2013, #329 (p.5)] <http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf>

End-of-life care in Russia

Hospital cuts add social welfare punch to Moscow's woes

RUSSIA | *The Washington Post* (U.S.) – 4 December 2014 – As the city's premiere public facility for palliative care of patients suffering from late-stage cancers, multiple sclerosis, and other serious illnesses, Hospital No. 11 is normally a placid place. But in the past several weeks, it has become the epicenter of a fast-growing protest against cuts to public health services – cutbacks so sweeping that they threaten to deliver the first major blow to the city's social welfare system in the country's ongoing economic crisis. By early next year, Moscow plans to shutter 28 hospitals and clinics – almost a quarter of its inpatient facilities – and downsize several dozen other medical centers in an "optimization" that will also reduce the city's medical staff by up to 10,000 positions. Doctors and nurses – government employees who rarely speak out – protested the impending moves twice last month. And opposition parties from across the political spectrum have joined demonstrations, decrying Moscow and Kremlin authorities for bad planning and bad timing. http://www.washingtonpost.com/world/europe/hospital-cuts-add-social-welfare-punch-to-moscows-woes/2014/12/03/03e74738-7a6c-11e4-8241-8cc0a3670239_story.html

Noted in Media Watch, 15 September 2014, #375 (p.9):

- *БЮЛЛЕТЕНЬ МЕДИЦИНСКИХ ИНТЕРНЕТ-КОНФЕРЕНЦИЙ* | Online – Accessed 10 September 2014 – '**Palliative medicine: Overview and statistics.**' Palliative care developments are now said to be under way, mostly in the hospital context, in all the regions of Russia. Yet the economic constraints of the 1990s have left health services chronically under-funded. In what is the largest geographic country of the world, the combined hospice and palliative care services are currently estimated at around 125 and the challenges are acknowledged as considerable. <http://cyberleninka.ru/article/n/palliative-medicine-overview-and-statistics>

N.B. Russian language article.

Home care in Scotland set to change

U.K. (Scotland) | BBC News – 2 December 2014 – Delivery of home social care in Scotland could be about to change. The Scottish government is considering new legislation to bring the provision of social work home care and health care together under one organisation. Social work care is currently run by local councils and health care by health boards. The Public Bodies Joint Working Scotland Bill will reduce the amount of time people spend in hospital, benefitting the elderly and those with long term health conditions and disabilities. <http://www.bbc.com/news/uk-scotland-30292675>

Articles on the integration of health and social services noted in past issues of Media Watch:

- U.K. (England) | Commission on the Future of Health & Social Care in England – 4 September 2014 – '**A new settlement for health and social care.**' The final report from the commission discusses the need for a new settlement for health and social care to provide a simpler pathway through the current maze of entitlements. It proposes an approach that redesigns care around individual needs regardless of diagnosis, and with a graduated increase in support as needs rise, particularly towards the end of life. [Noted in Media Watch, 8 September 2014, #374 (p.3)] <http://www.kingsfund.org.uk/publications/new-settlement-health-and-social-care>
- *INTERNATIONAL JOURNAL OF INTEGRATED CARE* | Online – 20 March 2014 – '**Integrated end-of-life care: The role of social services.**' If palliative care must be holistic, then it should include the social nature of the aid. [Noted In Media Watch, 31 March 2014, #351 (p.7)] <http://www.ijic.org/index.php/ijic/article/view/URN%3ANBN%3ANL%3AUI%3A10-1-114777/2376>

Cont.

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2014;4(18). **'Benefits of health and social care integration.'** Scotland's health boards and local authorities are moving towards integrated funding and service provision. [Noted in Media Watch, 24 March 2014, #350 (p.8)] <http://spcare.bmj.com/content/4/1/118.1.short>

Elder care in England

Home care services "close to crisis"

U.K. (England) | BBC News – 1 December 2014 – The home care system in England is close to crisis because of the way workers are exploited, a report says.¹ The review, led by former Care Minister Paul Burstow, found a combination of inadequate funding and poor working practices was putting people at risk. About 500,000 older and disabled people rely on home care for daily tasks such as washing and dressing. Some pay for it, but others get help from councils. But the report said zero-hours contracts and low pay was harming care. <http://www.bbc.com/news/health-30278034>

1. 'Key to Care: Report of the Burstow Commission on the future of the homecare workforce,' <http://www.lgiu.org.uk/briefings/>

End-of-life care in England

Dementia patients denied care towards end of life

U.K. (England) | *The Telegraph* – 1 December 2014 – Dementia sufferers lack proper care because the illness is not recognised as a terminal diagnosis, according to a report from two leading charities.¹ The report ... highlights the issues faced by dementia sufferers in the late stages of their lives and the barriers to the high-quality care they require. The report addressed the terminal nature of the illness, calling it "the forgotten aspect of what has been referred to as a silent epidemic." The report adds: "To date much of the focus has been on living well with dementia, with little focus on the experiences of people with dementia nearing the end of their lives." <http://www.telegraph.co.uk/health/elderhealth/11264103/Dementia-patients-denied-care-towards-end-of-life.html>

1. 'Living and Dying with Dementia in England: Barriers to care,' Marie Curie Cancer Care & Alzheimer's Society, December 2014. <http://www.mariecurie.org.uk/Documents/policy/dementia-report-executive-summary.pdf>

Noted in Media Watch, 18 August 2014, #371 (p.10):

- *JOURNAL OF ALZHEIMER'S DISEASE* | Online – 4 August 2014 – **'Needs of people with severe dementia at the end-of-life: A systematic review.'** Ten studies published from 1993-2013 were identified, encompassing qualitative, quantitative, and a mixed-methods study. Data synthesis yielded seven themes, with physical, social, and psychological needs the categories most frequently mentioned. <http://iospress.metapress.com/content/8wk34806v5630580/>

N.B. Several articles on end-of-life care for people living with dementia are noted in Media Watch, 23 June 2014, #363 (p.11).

[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.

The Liverpool Care Pathway

Inquiry follows death of 85-year-old woman less than a month before system was stopped

U.K. (England & Wales) | *The Daily Mail* – 1 December 2014 – The first police investigation into the death of an elderly hospital patient under the discredited Liverpool Care Pathway has begun, a police force revealed yesterday. The inquiry follows the death of 85-year-old Alice Johnson on a hospital ward in June – less than a month before the deadline set by ministers for the National Health Service to cease using the pathway. Mrs. Johnson was sent to hospital for assessment after staff at her care home suspected the onset of dementia. The Liverpool Care Pathway was supposed to ensure dignified and pain-free dying but it was scrapped after a scathing independent inquiry last year found it had meant "uncaring, rushed and ignorant" treatment of the most vulnerable patients.¹ <http://www.dailymail.co.uk/news/article-2855392/At-police-probe-Liverpool-Care-Pathway-death.html>

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. [Noted in Media Watch, 30 June 2014, #364 (p.7)] <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

Low palliative care use across Wales highlighted

U.K. (Wales) | BBC News – 1 December 2014 – Less than half of people who died from cancer and only 5% of those dying from other conditions received specialist palliative care, a report has found.¹ The ... [authors of the report] ... looked at figures from 2012, which also showed one in four hospital beds were used by patients in their last year of life in Wales. Older terminally ill people were much less likely to have palliative care. The Welsh government said there should be equal access to good care. The report highlighted "huge numbers" of admissions to hospitals and days spent in hospital by people in the last year of life. Out of all people who died in 2012, only a total of 17% accessed palliative care services. Of people with cancer aged over 85, only 35% used the services, compared to 58% of those aged up to 44. <http://www.bbc.com/news/uk-wales-30267931>

1. 'Death and dying in Wales: Analysis of inconsistencies in access to specialist palliative care and hospital activity in the last year of life,' Marie Curie & Bevan Foundation, December 2014. <http://www.mariecurie.org.uk/Documents/policy/Death%20and%20dying%20in%20Wales%20-%20exec%20summary.pdf>

Noted in Media Watch, 3 November 2014, #382 (p.8):

- U.K. (Wales) | Wales Online – 28 October 2014 – **'End-of-life care in Wales rated positively by patients and families in new report.'** An annual report on end-of-life care in Wales says a survey of patients and their families has rated services positively.¹ The report said 94% of 1,834 (survey) responses were overwhelmingly positive, with 22.6% receiving perfect scores. However the annual report also outlined areas that need to be addressed over the next year. <http://www.walesonline.co.uk/news/wales-news/end-of-life-care-wales-rated-positively-8007191>
1. 'Together for Health End-of-Life Care Delivery Plan: Annual Report 2014,' Health in Wales, Welsh Government. <http://wales.gov.uk/docs/dhss/publications/141024reporten.pdf>

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>

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

Death: A foe to be conquered? Questioning the paradigm

AGE & AGEING, 2015;44(1);7-10. We now primarily experience death through the lens of a camera. Representations of "death as spectacle" distort our perceptions and leave us ill-prepared for the reality. Additionally, death as a natural consequence of life has become much less visible than it was in the past due to our longer life expectancies and lack of infectious disease. The continued thrust for treatment, wedded with a failure to recognise the dying process, can rob individuals of a peaceful, dignified death. Progress being made in advance care planning and palliative care is limited by the existing paradigm of death as a "foe to be conquered." It is time for a shift in this paradigm. <http://ageing.oxfordjournals.org/content/44/1/7.abstract>

Of related interest:

- *JOURNAL OF ALLIED HEALTH*, 2014;43(4):212-220. **'Promoting health, wellness, and quality of life at the end of life: Hospice interdisciplinary perspectives on creating a good death.'** The purpose of this study was to answer the broad questions: What do professional caregivers for the dying think about what they do, and how does that thinking influence their practice in end-of-life care? <http://www.ncbi.nlm.nih.gov/pubmed/25433185>

Knowledge, skills, and attitudes in caring for older adults with advanced illness among staff members of long-term care and assisted living facilities

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 3 December 2014 – In long-term care and assisted living facilities, many groups of health care professionals contribute to the work of the health care team. These staff members perform essential, direct patient care activities. An educational needs assessment was conducted to determine the learning needs and preferences of staff members related to providing care for patients with life-limiting illnesses. Staff members placed importance on understanding topics such as principles of palliative care, pain assessment, pain management, and non-pain symptom management. The majority of survey respondents were also interested in learning more about these topics. The results of this analysis suggest staff members would benefit from a course tailored to these identified educational needs and designed to overcome previously identified educational barriers. <http://ajh.sagepub.com/content/early/2014/12/02/1049909114561996.abstract>

Human rights of the aged persons: Are we getting late to enforce their rights?

GLOBAL JOURNAL OF MULTIDISCIPLINARY STUDIES, 2014;3(12):79-94. There is an intrinsic tendency to look upon the aged individuals as one who has lived out just about all of his life with merely vegetative needs and no real hunger for recognition or identity. The feeling of being unwanted, beyond the prime, past one's usefulness all these weigh heavily upon the ageing. The economic needs of foods, shelter and clothing of the aged are modest. In most cases the resources of the aged are negligible, having been consumed *in toto* in the bringing up of their children. Most aged silently pray for an early end of their lives. <file:///C:/Users/Barry/Downloads/488-1058-1-SM.pdf>

Prison Hospice Backgrounder: Updated

The quality of end-of-life care in the corrections or prison system has been highlighted in Media Watch on a regular basis. A recently updated compilation of articles, reports, etc., noted in the weekly report has posted on the Palliative Care Community Network website: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>

Dying at home: A qualitative study of family carers' views of support provided by GPs community staff

BRITISH JOURNAL OF GENERAL PRACTICE, 2014;64(629):e796-e803. Dying at home is the preference of many patients with life-limiting illness. This is often not achieved and a key factor is the availability of willing and able family carers. Fifty-nine bereaved family carers were interviewed (54% response rate; 69% female). An overarching theme was of continuity of care that divided into personal, organisational, and informational continuity. Large numbers and changes in care staff diluted personal continuity and failure of the GPs to visit was viewed negatively. Family carers had low expectations of informational continuity, finding information often did not transfer between secondary and primary care and other care agencies. Organisational continuity when present provided comfort and reassurance, and a sense of control. The requirement for continuity in delivering complex end-of-life care has long been acknowledged. Family carers in this study suggested that minimising the number of carers involved in care, increasing or ensuring personal continuity, and maximising the informational and organisational aspects of care could lead to a more positive experience. <http://www.ncbi.nlm.nih.gov/pubmed/25452545>

Medical futility: A new look at an old problem

CHEST, 2014;146(6):1667-1672. Efforts to answer the question of whether or when physicians may unilaterally refuse to provide treatments they deem medically futile, but that are nonetheless demanded by patients or their surrogates, have been characterized as intractable failures. The authors propose a new look at this old problem and suggest reframing the debate in terms of the implicit social contract, in healthy democracies, between the medical profession and the society it serves. This ever-evolving contract is predicated upon providing patients with beneficial and desired medical care within the constraints of scarce resources and the characteristics of our health-care system. The contract ranges over a continuum of decisions, from those that do not need an explicit negotiated agreement with the patient or surrogate, to those that do. Between these two poles lies a contentious gray area, where the rights and obligations of patients and physicians are being shaped continuously by the many forces that are at play in a democratic society, including professional guidelines, social advocacy, legislation, and litigation. The authors provide examples of how this gray area has been and is negotiated around rights to refuse and demand a variety of life-sustaining treatments, and anticipate conflicts likely to arise in the future. <http://journal.publications.chestnet.org/article.aspx?articleid=1983728>

Of related interest:

- *JOURNAL OF BIOMEDICAL RESEARCH*, 2014;28(6):433–434. **'Autonomy and authority in medical futility.'** Medical futility has been proposed for many years to define the procedure that simply prolongs the suffering of patients but heals nothing. To deal with the decision procedure for treatment, two ideas arise: patients' autonomy and doctors' authority. Widely recognized in 1960s, patients' autonomy respected patients' willingness over treatment, requiring specific consent for treatment and right to choose during medical procedure. Another idea for futility is doctors' authority, explained from the paternalistic perspective as well. Modern medicine, which is based on patients' autonomy and doctors' authority, should attain a balance in between. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4250521/>

Noted in Media Watch, 1 December 2014, #386 (p.9):

- *CLINICAL RESEARCH & BIOETHICS* | Online – 31 October 2014 – **'Medical futility: Is a policy needed?'** Medical futility, once called "a problem without a name," remains a controversial issue in its definition as well as in its applications. The controversy exists, partly, in disagreements between families and physicians about the patient's best interests, the goals of treatment and the ends of medicine. <http://omicsonline.org/open-access/medical-futility-is-a-policy-needed-2155-9627.1000e102.pdf>

The use of palliative care to promote autonomy in decision making

CLINICAL JOURNAL OF ONCOLOGY NURSING, 2014;18(6):707-711. This article explores barriers to informed decision making in health care, and it proposes palliative care as one means of responding to the challenge of a widespread lack of autonomy in decision making. Through an exploration of research in the fields of autonomy and palliative care, the advantages of informed decision making and advance care planning by patients with advanced illness are discussed, and the implications for clinical practice and patient outcomes are described. Continuity, collaboration, and communication have a synergistic effect on autonomy. The expectation that the palliative care team will be in constant communication with the attending physician, nurses, and other specialists also promotes autonomous decision making. Patients who receive palliative care may have multiple advantages, including increased survival, improved quality of life, and opportunities for the exercise of autonomy. <http://ons.metapress.com/content/q425480338n20501/>

The boundaries of care work: A comparative study of professionals and volunteers in Denmark and Australia

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 2 December 2014 – This paper explores the manner in which two hospices – one located in Denmark and one in Australia – negotiate and determine the boundaries of volunteer workers *vis-à-vis* paid staff. A key finding is that volunteers in the Danish hospice were excluded from all direct care work due to the effective monopoly of the professional care providers, whereas the Australian volunteers participated in the provision of care to the extent that risk could be eliminated or mitigated to an acceptable level. The findings suggest two different models of the roles of volunteers in tension with professional care providers. Both models recognise that volunteers add to the level of care delivered by the organisations and allow for a discussion that moves away from the normative discussions of "not taking somebody's job," while also recognising that volunteers must be more than just the "nice extra" if they are to be of any real value to the organisation and to care receivers. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12154/abstract;jsessionid=6E7DF26544718AA077E83E7197AB5687.f03t01?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Societal costs of home and hospital end-of-life care for palliative care patients in Ontario, Canada

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 2 December 2014 – In Canada, health system restructuring has led to a greater focus on home-based palliative care as an alternative to institutionalised palliative care. However, little is known about the effect of this change on end-of-life care costs and the extent to which the financial burden of care has shifted from the acute care public sector to families. The purpose of this study was to assess the societal costs of end-of-life care associated with two places of death (hospital and home) using a prospective cohort design in a home-based palliative care programme. Societal cost includes all costs incurred during the course of palliative care irrespective of payer (e.g., health system, out-of-pocket, informal care-giving costs, etc.). The estimated total societal cost of end-of-life care was \$34,197.73 per patient over the entire palliative trajectory (4 months on average). Results showed no significant difference ... in total societal costs between home and hospital death patients. Higher hospitalisation costs for hospital death patients were replaced by higher unpaid caregiver time and outpatient service costs for home death patients. Thus, from a societal cost perspective, alternative sites of death, while not associated with a significant change in total societal cost of end-of-life care, resulted in changes in the distribution of costs borne by different stakeholders. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12170/abstract>

Cont.

Of related interest:

- **HEALTH & SOCIAL CARE IN THE COMMUNITY** | Online – 4 December 2014 – **'Task shifting in the provision of home and social care in Ontario, Canada: Implications for quality of care.'** Growing healthcare costs have caused home-care providers to look for more efficient use of healthcare resources. Task shifting is suggested as a strategy to reduce the costs of delivering home-care services. Task shifting refers to the delegation or transfer of tasks from regulated healthcare professionals to home-care workers (HCWs). The purpose of this paper is to explore the impacts of task shifting on the quality of care provided to older adults from the perspectives of home healthcare workers. A thematic analysis of the data revealed mixed opinions on the impacts of task shifting on the quality of care. HCWs and their supervisors, more often than nurses and therapists, felt that task shifting improved the quality of care through the provision of more consistent care; the development of trust-based relationships with clients; and because task shifting reduced the number of care providers entering the client's home. Policy implications for regulating bodies, employers, unions and educators are discussed. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12168/abstract>

Moral distress among healthcare professionals: Report of an institution-wide survey

JOURNAL OF NURSING SCHOLARSHIP | Online – 29 November 2014 – Five hundred ninety-two clinicians completed usable surveys. Moral distress was present in all professional groups. Nurses and other professionals involved in direct patient care had significantly higher moral distress than physicians and other indirect care professionals. Moral distress was negatively correlated with ethical workplace climate. Watching patient care suffer due to lack of continuity and poor communication were the highest-ranked sources of moral distress for all professional groups, but the groups varied in other identified sources. Providers working in adult or intensive care unit (ICU) settings had higher levels of moral distress than did clinicians in pediatric or non-ICU settings. Providers who

left or considered leaving a position had significantly higher moral distress levels than those who never considered leaving. <http://onlinelibrary.wiley.com/doi/10.1111/jnu.12115/abstract;jsessionid=7AD2D650B814F91C276CF84B1FE8E442.f04t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Extract from *Journal of Nursing Scholarship* article

Providers who had training in end-of-life care had higher average levels of moral distress than those without this training.

From Albania to Zambia: Travel back to country of origin as a goal of care for terminally ill patients

JOURNAL OF PALLIATIVE MEDICINE | Online – 3 December 2014 – With unprecedented levels of international migration, physicians in the U.S. may care for terminally ill patients who have strong connections to their country of origin and such patients may desire to return in the final stages of life. In this study, the authors analyzed how often terminally ill patients cited travel to country of origin as a goal of care, how often travel occurred, and factors associated with successful travel. Of 336 foreign-born patients, 129 (38%) expressed a desire to travel to their country of origin; 60 (47%) successfully returned to 24 unique countries. Countries to which the largest number of patients returned were Mexico, Poland, and the Philippines. Although patients with the best functional status were most likely to travel successfully, 16 (31%) who wanted to travel despite having the worst functional status ... traveled successfully. There were no deaths *en route* or flight diversions due to medical crisis; all trips were made on regularly scheduled commercial airline flights. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0267>

Cont.

Noted in Media Watch, 18 August 2014, #371 (p.11):

- *SUPPORTIVE CARE IN CANCER* | Online – 16 August 2014 – '**I want to fly home: A terminal cancer patient's right to go home.**' As palliative care physicians, we sometimes find ourselves immersed in the dilemma of a patient with terminal cancer requesting to fly back home, often overseas. This particular situation is filled with an array of complex variables: establishing that the medical condition is stable enough for overseas travel, dealing with a significant cost (sometimes in patients with scarce economical resources), securing proper care on the receiving end, symptom management during flight, and dealing with the possibility of in-flight death, among others. <http://link.springer.com/article/10.1007/s00520-014-2391-0>

Noted in Media Watch, 10 September 2012, #270 (p.4):

- *AIR MEDICAL JOURNAL*, 2012;31(5):238-241. '**Air medical repatriation: Compassionate and palliative care consideration during transport.**' The number of elderly international travelers continues to increase. Many are afflicted with multiple ... medical conditions; a significant portion of these elderly travelers are considered end stage with respect to their disease state. While traveling, they are exposed to travel hazards and deterioration of their already compromised health. <http://www.sciencedirect.com/science/article/pii/S1067991X11002483>

Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents

JOURNAL OF PALLIATIVE MEDICINE | Online – 3 December 2014 – Preparedness for death as a predictor of post-bereavement adjustment has not been studied prospectively. Little is known about pre-death factors associated with feeling prepared prior to the death of a loved one. CGs [informal caregivers] who reported feeling more prepared for the death experienced lower levels of complicated grief post-bereavement. A multivariate ordinal logistic regression model showed that spouses as opposed to adult child CGs were less prepared for the death, depressed CGs were less prepared, and patients who engaged in advance care planning had CGs who felt more prepared. CR overt expressions about wanting to die was also related to higher levels of preparedness in the CG. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0309>

A community for grieving: Affordances of social media for support of bereaved parents

NEW REVIEW OF HYPERMEDIA & MULTIMEDIA | Online – 27 November 2014 – The purpose of this paper was to study bereaved parents' use of a closed peer grief support community on Facebook and the features of the community important to them. The death of a child is an uncomfortable subject in most contemporary societies. This limits the exploration of experiences and possibilities for coping with grief. With the introduction of social media, this has changed. Theoretical perspectives on parental grief recognizing the importance of continued relational bonds with the lost child are used, together with the ontological assumption that social media enhance the dissolving of private/public and time/space. The results [of this study] show how the affordances of social media become vital resources for coping with grief in ways not available previously, comprising aspects of the closed nature of the group, shared experiences, time, and accessibility. http://www.tandfonline.com/doi/abs/10.1080/13614568.2014.983557#.VH3R6tLF_YQ

Noted in Media Watch, 3 November 2014, #382 (p.13):

- *JOURNAL OF SOCIAL & PERSONAL RELATIONSHIPS* | Online – 21 October 2014 – '**Death on Facebook: Examining the roles of social media communication for the bereaved.**' This study examines the ways in which the social networking site Facebook was helpful and unhelpful to participants when someone they knew died. Analysis revealed three themes describing participants' experiences ... during bereavement: news dissemination, preservation, and community. <http://spr.sagepub.com/content/early/2014/10/21/0265407514555272.abstract>

Integration of oncology and palliative care: A systematic review

THE ONCOLOGIST | Online – 5 December 2014 – Both the American Society of Clinical Oncology and the European Society for Medical Oncology strongly endorse integrating oncology and palliative care (PC); however, a global consensus on what constitutes integration is currently lacking. To better understand what integration entails, the authors conducted a systematic review to identify articles addressing the clinical, educational, research, and administrative indicators of integration. Of the 431 publications in their initial search, 101 were included. A majority were review articles (58%) published in oncology journals (59%) and in or after 2010. This systematic review highlighted 38 clinical, educational, research, and administrative indicators. <http://theoncologist.alphamedpress.org/content/early/2014/12/04/theoncologist.2014-0312.abstract>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL OPEN*, 2014;2(4):e262-e267. **'Characteristics of Belgian "life-ending acts without explicit patient request": A large-scale death certificate survey revisited.'** "Life-ending acts without explicit patient request," as identified in robust international studies, are central in current debates on physician-assisted dying. Despite their contentiousness, little attention has been paid to their actual characteristics and to what extent they truly represent non-voluntary termination of life. Most of the cases we studied did not fit the label of "non-voluntary life-ending" for at least one of the following reasons: the drugs were administered with a focus on symptom control; a hastened death was highly unlikely; or the act was taken in accordance with the patient's previously expressed wishes. Thus, we recommend a more nuanced view of life-ending acts without explicit patient request in the debate on physician-assisted dying. <http://www.cmajopen.ca/content/2/4/E262.abstract>

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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.

Links to Sources

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4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
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.

- *INTERNATIONAL NURSING REVIEW* | Online – 1 December 2014 – **'Nurses and the euthanasia debate: Reflections from New Zealand.'** In New Zealand, euthanasia remains illegal, but in 2012, the End of Life Choice Bill was put in the ballot for potential selection for consideration by Parliament, later to be withdrawn. However, it is increasingly likely that New Zealand will follow international trends to offer people a choice about how their lives should end, and that such a Bill will be resubmitted in the near future. Undoubtedly, the passage of such legislation would have an impact on the day-to-day practices of nurses who work with dying people. New Zealand nurses will eventually have an opportunity to make their views on proposed euthanasia legislation known, and what such legislation might mean for their practice. Nurses everywhere should seriously consider their own knowledge and viewpoint on this vitally important topic, and be prepared to respond as both individuals and as part of their professional bodies when the time inevitably arrives. The result will be a better informed set of policies, regulations and legislation leading to a more meaningful and dignified experience for dying people and their families. <http://onlinelibrary.wiley.com/doi/10.1111/inr.12145/abstract>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/10/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 | 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://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>

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