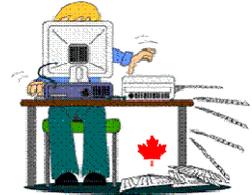


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Effecting change in the illness experience: Scroll down to [Specialist Publications](#) and 'Revisiting perceptions of quality of hospice care: Managing for the ultimate referral' (p.7), in *American Journal of Hospice & Palliative Medicine*.

Canada

Expected precedent-setting case

Patient's family sues B.C. as nursing home keeps her alive against her wishes

BRITISH COLUMBIA | *The Vancouver Sun* – 6 August 2013 – The actions of Abbotsford nursing home staff who are spoon-feeding an 82-year-old Alzheimer's patient – contrary to the wishes she expressed in her living will – constitute battery, a lawsuit by her daughter and husband alleges. The lawsuit, filed in B.C. Supreme Court against Fraser Health, the nursing home, and the provincial government, is expected to be precedent-setting as it should clarify end-of-life rights of patients and the obligations of health providers. The patient, Margaret (Margot) Bentley, is a former nurse and the daughter of Charles Tysoe, who was a B.C. Court of Appeal judge. She frequently reminded relatives and friends that she had executed the legal document, the suit states. Katherine Hammond, Bentley's daughter and co-plaintiff ... said that her mother would have shunned the public spotlight and would never have wanted to become a right-to-die "test case." <http://www.vancouversun.com/health/Patient+family+sues+Victoria+over+living+will/8756167/story.html>

End-of-life policy for adults living with developmental disabilities and their families

BRITISH COLUMBIA | Community Living British Columbia (CLBC) – 18 July 2013 – CLBC has updated its end-of-life policy that outlines responsibilities of CLBC staff and contracted service providers for the reporting, documenting and review required following the death of an individual supported by CLBC funded services. CLBC delivers supports and services to adults with developmental disabilities and their families. <http://www.communitylivingbc.ca/about-us/policies/end-of-life-policy/>

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 focuses on dying and death and people living with intellectual disabilities. Contents: <http://onlinelibrary.wiley.com/doi/10.1111/jar.2013.26.issue-3/issuetoc>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 5 August 2013 – **'Only one in four doctors would help terminally ill patients end their lives if practice was legal in Canada.'** Only 25% of the nation's doctors would be willing to help terminally ill patients end their lives if the practice of doctor-assisted suicide were legalized, a survey by Canada's biggest doctors' group suggests. <http://news.nationalpost.com/2013/08/05/only-one-in-four-doctors-would-help-terminally-ill-patients-end-their-lives-if-practice-was-legal-in-canada/>

Noted in Media Watch, 18 February 2013, #293 (p.8):

- CANADIAN MEDICAL ASSOCIATION | Online – 8 February 2013 – **'Physician views on end-of-life issues vary widely.'** A survey of members' views on major end-of-life issues found that only 20% of respondents would be willing to participate if euthanasia is legalized in Canada. http://www.cma.ca/index.php?ci_id=205556&la_id=1

U.S.A.

Eleven states get failing grades for nursing home care

FLORIDA | CBS Evening News (Tallahassee) – 9 August 2013 – More than one-and-a-half million Americans live in nursing homes, but the quality of care varies greatly. For the first time ... [a new report¹] ... states do a good job of caring for seniors and which fail to ensure that they won't be neglected or abused. States that got As: Alaska, Rhode Island, New Hampshire, Hawaii, Oregon, Maine, Utah, Idaho, South Dakota and North Dakota. States that got Fs: Texas, Louisiana, Indiana, Oklahoma, Missouri, New Mexico, New York, Michigan, Nevada, Illinois and Iowa. http://www.cbsnews.com/8301-18563_162-57597944/eleven-states-get-failing-grades-for-nursing-home-care/

1. 'Nursing Home Report Cards,' Families for Better Care, August 2013. <http://nursinghomereportcards.com/>

One surprising reason elders don't get optimal end-of-life care

CARE 2 | Online – 8 August 2013 – Nearly one-third of elderly Americans turn to skilled nursing care during their last few months of life, despite the fact that some may be better served by seeking palliative care services, such as hospice, according to a recent analysis.^{1,2} Researchers from the University of California, San Francisco, discovered that 31% of Medicare beneficiaries who were newly released from the hospital utilized the program's skilled nursing benefit ... in their last six months of life. What was surprising was that many of these aging adults failed to take advantage of Medicare hospice coverage during this time, even though elders who reside in nursing homes can apply to receive additional palliative care if they are close to death. This finding raises the question of whether or not these ailing adults are getting the optimal care for their terminal conditions. <http://www.care2.com/greenliving/one-surprising-reason-elders-dont-get-optimal-end-of-life-care.html>

Cont.

1. 'Use of the Medicare posthospitalization skilled nursing benefit in the last 6 months of life,' *Archives of Internal Medicine*, 2012;172(20):1573-1579. [Noted in Media Watch, 8 October, #274 (p.2)] <http://archinte.jamanetwork.com/article.aspx?articleid=1368358>
2. Comment on 'Use of the Medicare posthospitalization skilled nursing benefit in the last 6 months of life,' *Archives of Internal Medicine*, 2012;172(20):1580-1581. [Noted in Media Watch, 8 October, #274 (p.2)] <http://archinte.jamanetwork.com/article.aspx?articleid=1368352>

Where did mom keep the will? Is there a will?

MICHIGAN | University of Michigan Extension – 7 August 2013 – Many families avoid having this emotionally charged discussion. By not knowing what has been put in place, families are faced making many decisions at an uncomfortably fast pace. Planning ahead can lead to peace of mind for parents and grown children. The most important piece of this process is communication and specifically, communication with all family members. Once a member of the family feels left out of decision making conversations, trouble starts. We live in an era of accessing each other through conference calls, email and text messages. Decisions need not be made without all family members. Siblings need to be patient and respectful of others reactions and feelings. During these conver-

sations, tendency is to slip into the same roles we had when growing up together. Keep this in mind when the oldest starts to seemingly boss everyone around or the youngest whines that no one tells her anything. Focus on ... honoring your parent(s). http://msue.anr.msu.edu/news/where_did_mom_keep_the_will_is_there_a_will

When is the best time for a meeting?

It might be easier to list when not to hold a meeting. Stay away from holiday visits, family reunions or at the end of a hospital bed. Set a specific place and time for this important conversation and don't forget to include your parent(s).

Of related interest:

- RHODE ISLAND | ABC News – 9 August 2013 – '**Young doctors pave way for end-of-life conversations.**' Doctors at Kent Hospital are breaking new ground – but it's not the old guard – it's the residents, those doctors fresh out of medical school and in the throes of training, who are demanding to be taught how to interact with their patients preparing for end-of-life care. <http://abcnews.go.com/blogs/health/2013/08/09/young-doctors-pave-way-for-end-of-life-conversations/>

New York caregiving crisis: 61% of 50+ New Yorkers worried about staying in home as they get older

NEW YORK | American Association of Retired Persons (AARP) – 6 August 2013 – In a new survey, AARP found New Yorkers 50-plus are concerned about their ability to stay in their home as they age and overwhelmingly want services available to help them to do so. The survey reveals that a large number of New Yorkers anticipate needing to provide care to a family member or friend and see a role for New York State in providing supports and services. Unpaid, informal family caregivers play a vital role in the delivery of long-term care in New York State. An estimated 4.1 million caregivers in New York provide 2.68 billion hours of unpaid care valued at \$32 billion dollars annually. <http://states.aarp.org/ny-caregiving-crisis-61-of-50-new-yorkers-worried-about-staying-in-home-as-they-get-older/>

1. AARP Survey: <https://docs.google.com/file/d/0B2jFuiFNmX4UHBGTnJNNjBXOE0/edit?pli=1>

Prisons get grayer, but efforts to release the dying lag

NEW YORK | *City Limits* – 6 August 2013 – From 2007 to 2012 ... the elderly prisoner population increased by 27.7%, according to the New York State Department of Corrections & Community Service. Due to long sentences handed out in the 70s and 80s, American prisons now serve as quasi-nursing homes, albeit lacking the long-term care we associate with geriatric facilities. The state's Compassionate Release Program aims to reduce the number of elderly and sick in prison. But the process is cumbersome and lengthy, with the majority of

eligible inmates dying before release. <http://www.citylimits.org/news/articles/4871/prisons-get-grayer-but-efforts-to-release-the-dying-lag>

Specialist Publications

'Administrators' perspectives on changing practice in end-of-life care in a state prison system' (p.10), in *Public Health Nursing*.

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of p.11.

Obamacare rolls out hospice care penalties and quality focus

FORBES | Online – 4 August 2013 – Providers of hospice care ... were told they get a 1% pay raise from Medicare and a mandate to report quality measures to the U.S. government or essentially lose that raise... The Affordable Care Act, which has pushed myriad quality measures for providers and health insurance companies, said hospices that fail to "meet quality reporting requirements will receive a two percentage point reduction to their market basket..." The move comes at a time hospitals, doctors and providers of medical-care of all kinds are being coaxed away from fee-for-service medicine to an era when they are paid based on the value of medical care that they provide. <http://www.forbes.com/sites/brucejapsen/2013/08/04/obamacare-rolls-outs-hospice-care-penalties-and-quality-focus/>

Specialist Publications

'Revisiting perceptions of quality of hospice care: Managing for the ultimate referral' (p.7), in *American Journal of Hospice & Palliative Medicine*.

'A descriptive study of California hospice providers' perceptions of public reporting of quality data using the Family Evaluation of Hospice Care Survey' (p.7), in *American Journal of Hospice & Palliative Medicine*.

'Hospice for nursing home residents: Does ownership type matter?' (p.10), in *Journal of Palliative Medicine*.

Of related interest:

- *MCKNIGHT'S LONG TERM CARE NEWS & ASSISTED LIVING* | Online – 5 August 2013 – **'New bill emphasizes freedom in serious illness care plans.'** A newly proposed bill aims to give people with serious and terminal illnesses more say in their care plan and provide Medicare and Medicaid reimbursement to healthcare professionals for holding discussions about a patient's goals, illness and treatment options. <http://www.mcknights.com/new-bill-emphasizes-freedom-in-serious-illness-care-plans/article/305878/>

Media Watch Online

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care community-at-large. See a complete listing on p.11.

International

End-of-life care in Australia

Funds to access palliative care for ethnic communities

AUSTRALIA (VICTORIA) | Pro Bono News – 9 August 2013 – Victorian Government has provided Palliative Care Victoria with funding to work with multicultural organisations to raise awareness of palliative care for people with a Culturally & Linguistically Diverse (CALD) background. Almost 24% of Victorians were born overseas; however people from CALD backgrounds only account for 7% of palliative care clients. Health Minister David Davis said the Culturally Responsive Palliative Care Community Education project would engage with the Chinese, Italian, Maltese, Turkish and Vietnamese communities. <http://www.probonoaustralia.com.au/news/2013/08/funds-access-palliative-care-ethnic-communities>

Noted in Media Watch, 12 March 2012, #244 (p.9):

- *ASIA-PACIFIC JOURNAL OF CLINICAL ONCOLOGY*, 2012;8(1):3-9. **'Development and measurement of palliative care cultural standards using clinical indicators.'** Although there have been many efforts by the Australian Government to establish culturally sensitive health services over the last 30 years or so, more work is required to ensure that culturally sensitive end of life care is provided, especially because of differences in culture and traditions at the end stage of life. <http://onlinelibrary.wiley.com/doi/10.1111/j.1743-7563.2011.01510.x/full>

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

Cancer patients "denied care and dignity by National Health Service"

U.K. (ENGLAND) | *The Daily Express* – 9 August 2013 – Tens of thousands of cancer patients a year are being denied basic care and dignity in hospital, a report reveals. Patients say their medical files have been lost, putting their health at serious risk. They add that they are "humiliated" by nurses and forced to wait to go to the toilet. One in 10 patients staying overnight said he or she was examined on an open ward or with the curtain round their bed partly open. A survey found that of the 170,000 cancer victims admitted to hospitals in England each year, around 18,000 – or 11% – said their files were lost by a doctor or nurse. Some 15% felt they were belittled by nurses while 14% were forced to wait at least 30 minutes after asking for help to go to the toilet – one per cent waited for at least two hours. The survey of 2,217 adults was carried out by YouGov for the charity Macmillan Cancer Support. <http://www.express.co.uk/news/health/420729/Cancer-patients-denied-care-and-dignity-by-NHS>

Making the end of life better

U.K. (ENGLAND) | *The Lancashire Evening Post* – 6 August 2013 – A ground breaking programme to improve end-of-life care within care homes across the north-west is having a positive impact, according to new research. Edge Hill University's Evidence-based Practice Research Centre [EPRC] was asked to explore the impact of a programme developed to help train staff in care homes to deal with end of life residents. Dr. Mary O'Brien, Reader in Health Research in the EPRC, led the study with a number of colleagues. <http://www.lep.co.uk/news/health/local/making-the-end-of-life-better-1-5921744>

N.B. Overview of the University's Evidence-based Practice Research Centre study: <http://www.edgehill.ac.uk/news/2013/08/research-shows-care-home-residents-get-their-dying-wish/>

Specialist Publications

'End-of-life communication: A retrospective survey of representative general practitioner networks in four countries [The Netherlands, Belgium, Spain and Italy]' (p.9), in *Journal of Pain & Symptom Management*.

Pan-palliative care

Dying for pain relief: Blending the art and science of medicine

SOUTH AFRICA | *The Financial Mail* (Johannesburg) – 5 August 2013 – Pan-palliative care is the title Dr. [Selma] Browde [founder and director of the multidisciplinary hospital palliative care team at Charlotte Maxeke Johannesburg Academic Hospital] coined for an expanded approach [to end-of-life care] that she developed in 1998, and she says it was a world first at the time. Pan-palliative care centres on the principles of a relatively new discipline of narrative medicine – the importance of doctors listening to patients' "stories." Their feelings, habits, fears, beliefs and concerns – can play a role in illness or injury and are proved scientifically to affect the perception of pain and treatment outcomes. Doctors do take a medical history – a patient's medical condition, including tests, treatments and medication that may have been prescribed, says Dr. Browde. They are not, however, properly trained to listen to patients' narratives, even if they have the time or inclination to do so. But pan-palliative care goes beyond doctors listening attentively to patients and the conventional definition of palliative care – a term closely associated in the minds of many people (and many doctors) with the pain of terminal illness and so-called end-of-life care, especially in the case of people with cancer, and in this country, Aids-related illnesses. <http://www.bdlive.co.za/life/health/2013/08/06/dying-for-pain-relief-blending-the-art-and-science-of-medicine>

Noted in Media Watch, 7 February 2011, #187 (p.9):

- *ILLNESS, CRISIS & LOSS*, 2011;19(1):27-39. **'The inhospitable hospital.'** Personal illness narratives are used to highlight deficiencies in hospital care and challenge hospitals to become more hospitable and less like factories for treating illnesses. An alienating hospital environment where staff focuses on technical tasks and functions can drive patients and family members into a state of deep isolation and disconnectedness just when they need compassion... <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,3,11;journal,1,49;linkingpublicationresults,1:103734,1>

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

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
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.

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

Revisiting perceptions of quality of hospice care: Managing for the ultimate referral

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 August 2013 – Hospice services provided in the final months of life are delivered through complex interpersonal relationships between caregivers, patients, and families. Often, service value and quality are defined by these interpersonal interactions. This understanding provides hospice leaders with an enormous opportunity to create processes that provide the optimal level of care during the last months of life. The ultimate referral is attained when a family member observes the care of a loved one, and the family member conveys a desire to receive the same quality of services their loved one received at that facility. This article provides evidence that supports the methods to ultimately enhance the patient's and family's experience and increase the potential for the ultimate referral. <http://ajh.sagepub.com/content/early/2013/08/07/1049909113499441.abstract>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 August 2013 – **'A descriptive study of California hospice providers' perceptions of public reporting of quality data using the Family Evaluation of Hospice Care Survey.'** The Affordable Care Act requires U.S. hospices to report quality data to the Centers for Medicare & Medicaid Services (CMS) in 2013 with data eventually being made public. There may be some benefit to participating in a voluntary public-reporting program prior to public disclosure by CMS; therefore, the authors developed and conducted an electronic survey exploring California hospices' perceptions of public reporting. The majority (78.1%) of respondents reported current use of the Family Evaluation of Hospice Care tool and a willingness to consider voluntary participation in a public-reporting program outside of what is being implemented by CMS (58.6%). <http://ajh.sagepub.com/content/early/2013/07/31/1049909113497418.abstract>

Utilization and cost of services in the last 6 months of life of patients with cancer – with and without home hospice care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 August 2013 – Detailed information was extracted from the health care electronic administrative data files on 193 deceased cancer patients ... [whose] ... family approved the study. About 88% had been hospitalized for 19 days on average and 53% visited the ER. One quarter received home-hospice care. Their average cost was \$13,648 compared to \$18,503 for patients without home-hospice care. Hospitalization contributed 32% to the total cost of patients with home-hospice care and 64% for those with it. The findings support the justification for significant expansion of home-hospice care. <http://ajh.sagepub.com/content/early/2013/08/07/1049909113499604.abstract>

Cont. next page



Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or 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 courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

Of related interest:

- *CONTEMPORARY NURSE* | Online – 4 August 2013 – **'Home is where I want to die: Kelly's Journey.'** The preferred place of death has been highlighted as an important concept in defining a good death. 70% of Australians express the desire to spend their last days at home. In reality only 16 % of people die at home. 10% of Australians die in residential aged care facilities and approximately 20% in hospices; the rest die in hospitals. Family support and the family's care giving ability play a major role in determining whether a person is able to die at home. <http://www.contemporarynurse.com/archives/vol/46/issue/2/article/5235/home-is-where-i-want-to-die-kelly%E2%80%99s-journey>

Longing for the smallest shred of hope

A matter of conscience

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 5 August 2013 – "Why do patients die? Not because of what I do, but in spite of everything I did," answered Dr. Wright, confused by the ethicist, who wanted to discuss the goals of care for his elderly patient with dementia. "There is nothing I will not offer or do in support of life and my reason is simple. I am a doctor. I have taken an oath to do no harm, and there is no greater harm than death. Who am I to take one single day away from a living soul when there is something that can be done? You have to be there when a husband or a child looks right into your eyes and asks 'Is she going to be all right? Is she going to live? Can't you do something, anything, doctor?' I sense their pain, their grief, the longing for the smallest shred of hope. When we get to that place, they know, and I know, we are getting to the end, but still, the smallest shred of hope is all they are asking for." <http://ajh.sagepub.com/content/early/2013/07/31/1049909113494749.extract>

Noted in Media Watch, 9 May 2011, #200 (p.8):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2011;305(17):1804-1805. **'Would accommodating some conscientious objections by physicians promote quality in medical care?'** Genuine conscience-based refusals are refusals in which a physician believes providing the requested service would violate his or her core moral beliefs (religious or secular), thereby causing personal moral harm. <http://jama.ama-assn.org/content/305/17/1804.extract>

Noted in Media Watch, 14 March 2011, #192 (p.3):

- *JOURNAL OF MEDICAL ETHICS* | Online – 9 March 2011 – **'Conscientious refusals to refer: Findings from a national physician survey.'** There is no uncontroversial way to resolve conflicts posed when patients request interventions that their physicians cannot in good conscience provide. <http://jme.bmj.com/content/early/2011/03/09/jme.2010.041194.abstract>

In denial: The role of law in preparing for death

THE ELDER LAW JOURNAL | Online – Accessed 8 August 2013 – End of life law, though flawed, offers some opportunity to express one's values and preferences via advance directives, health care proxies, and other such mechanisms, in order to prepare for death before it is imminent. Yet many people avoid the thinking process that is necessary to make these preparations because the thought of death is uncomfortable to confront. Most decide, consciously or unconsciously, not to decide. If the decision not to decide is the result of a voluntary and considered choice to accept mortality by relinquishing attempts to exert control over death and the dying process, then perhaps all is well, at least for the dying individual, though the medical technology juggernaut may result in an undesirable prolongation of the process. If, however, the non-decision arises out of a reluctance and fear to confront death, then the non-decidors do themselves a disservice, not only at the time of death, but throughout the life that precedes it. <https://litigation-essen-tials.lexisnexis.com/webcd/app?action=DocumentDisplay&crawlid=1&doctype=cite&docid=21+Elder+L.J.+1&srctype=smi&srcid=3B15&key=3bf1dd011129a72a427d993b3ce84225>

Cont.

Of related interest:

- *BRITISH JOURNAL OF CARDIAC NURSING*, 2013;8(8):404-406. **"Do not attempt resuscitation" orders: A review of the law.** Controversy surrounding the use of do not resuscitate orders on patients often without their knowledge and without apparent good reason have led some to question the lawfulness of such orders. The author considers the legal basis for do not resuscitate orders and outlines decisions from the courts... http://www.cardiac-nursing.co.uk/cgi-bin/go.pl/library/article.html?uid=100148;article=cn_8_8_404_406

Improving the end-of-life for people with dementia living in a care home: An intervention study

INTERNATIONAL PSYCHOGERIATRICS | Online – 7 August 2013 – One in three adults, most of whom are living in a care home at the time, dies with dementia. Their end-of-life is often in hospital, where they may experience uncomfortable interventions without known benefit and die rapidly with uncontrolled pain and comfort needs. This small non-randomized study is the first end-of-life care in dementia intervention to report an increase in family satisfaction with a reduction in hospital deaths. This is promising but requires further evaluation in diverse care homes. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8968126&fulltextType=RA&fileId=S1041610213001221>

Noted in Media Watch, 8 July 2013, #313 (p.10):

- *PALLIATIVE MEDICINE* | Online – 4 July 2013 – **'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care.'** The authors provide the first definition of palliative care in dementia ... [and] ... a framework to provide guidance for clinical practice, policy and research. 64 experts from 23 countries evaluated a set of 11 domains and 57 recommendations. <http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract>

N.B. Noted in Media Watch, 14 January 2013, #288 (pp.8-9), are several articles from past issues of the weekly report on end-of-life care for people living with dementia.

End-of-life communication: A retrospective survey of representative general practitioner networks in four countries

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 9 August 2013 – In total, 4,396 non-sudden deaths were included [in this cross-sectional, retrospective survey]. On average, more topics were discussed in The Netherlands, followed by Belgium, Spain, and Italy. The topics most frequently discussed in all countries were "physical complaints" and the "primary diagnosis," whereas "spiritual and existential issues" were the least frequently discussed. Discussions were most prevalent in The Netherlands, followed by Belgium. The GPs from all countries tended to discuss fewer topics with older patients, non-cancer patients, patients with dementia, patients for whom palliative care was not an important treatment aim, and patients for whom their GP had not provided palliative care. [http://www.jpsmjournal.com/article/S0885-3924\(13\)00331-X/abstract](http://www.jpsmjournal.com/article/S0885-3924(13)00331-X/abstract)



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

12 October 2013

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

Hospice for nursing home residents: Does ownership type matter?

JOURNAL OF PALLIATIVE MEDICINE | Online – 30 July 2013 – Currently, more than half of all nursing home residents use hospice at some point. Studies have shown benefits to hospice enrollment for patients; however, the literature on ownership differences in hospice care in general has indicated that for-profit hospices offer a narrower scope of services and employ fewer professional staff. Although nursing home staffing patterns have been shown to be essential to quality of care, the literature has not explored differences in number of patients per staff member for hospice care within nursing homes. Adjusted analysis [using data from the National Hospice Survey] indicated a higher number of patients per staff member for HCWs [home care workers] and RNs among for-profit hospices. Moreover, compared with non-profit hospices, for-profit hospices with a high proportion of nursing home residents had 36 more patients per HCW and 24 more patients per RN. <http://online.liebertpub.com/doi/full/10.1089/jpm.2012.0544>

Research on psychological and social factors in palliative care

PALLIATIVE MEDICINE | Online – 9 August 2013 – A variety of factors, including methodological limitations, protective attitudes of health-care providers, and the progressive deterioration of patients with terminal disease, have presented obstacles to psychosocial research in palliative care. The more recent development of valid and reliable measures of psychological distress and psychological well-being has significantly advanced research in the field. Pilot studies and randomized controlled trials of psychosocial interventions have yielded promising results, although the demonstrated impact on primary outcomes in these studies has typically been modest. Psychosocial research in palliative care has grown in rigor and volume over the past several decades, and a variety of novel interventions have been developed and evaluated. However, the findings from this research have only begun to have an impact on clinical practice in palliative care. <http://pmj.sagepub.com/content/early/2013/08/07/0269216313499961.abstract>

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 9 August 2013 – '**Observations of professional-patient relationships: A mixed-methods study exploring whether familiarity is a condition for nurses' provision of psychosocial support.**' The data disconfirm the belief that familiarity is either a necessary or sufficient condition for the provision of psychosocial support. Nurses familiar with patients did not necessarily respond to patients' psychosocial needs, and nurses with no prior contact with the patient immediately dealt with psychosocial needs. <http://pmj.sagepub.com/content/early/2013/08/07/0269216313499960.abstract>

Administrators' perspectives on changing practice in end-of-life care in a state prison system

PUBLIC HEALTH NURSING | Online – 5 August 2013 – Sentencing trends have created a demographic shift in prison populations. Greater numbers of inmates are aging and dying in prison, creating a demand for enhanced end-of-life (EOL) care. Changing practice to meet escalating care demands ... is complicated by economic constraints, attitudinal barriers, and organizational features. This study explored perspectives of EOL care held by administrators in a state prison system to reveal challenges to changing practice to meet the needs of inmates suffering advanced illness and dying in prison. Influences impacting EOL services: local prison culture, treatment versus security focus, case-by-case consideration, public sentiment, budget neutral approaches and conflicting views of service targets. Findings revealed the organizational structures, attitudes, and beliefs held by the administrative echelon of a state prison system and were used to guide the derivation of discrete approaches to changing practice in this complex system. <http://onlinelibrary.wiley.com/doi/10.1111/phn.12069/abstract;jsessionid=32B885C6C14D0DA288032212907A5706.d04t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Worth Repeating

The problem of caring for the dying in a general hospital: The palliative care unit as a possible solution

CANADIAN MEDICAL ASSOCIATION JOURNAL, 1976:115(2):119-121. The general hospital as a setting for terminal care has disturbing deficiencies: particularly, the medical, emotional and spiritual needs of the patients and their families are generally neglected. Consideration of the options for improving the situation led to the opening of the palliative care unit (PCU) at the Royal Victoria Hospital, Montreal, staffed by an interdisciplinary team with a positive and creative attitude to death and bereavement. Palliative care service comprises three areas of care – the PCU itself, a domiciliary service, and a consultative service – as well as research, teaching and administrative functions. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1878558/pdf/canmedaj01484-0031.pdf>

Media Watch Online

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: [HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/](http://APHN.ORG/CATEGORY/MEDIA-WATCH/)

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> (Scroll down to 'International Websites' to 'Palliative Care Network' to access the weekly report)

Canada

ONTARIO | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <http://www.hnhbhpc.net/CurrentNewsandEvents/tabid/88/Default.aspx> (Click on 'Current Issue' under 'Media Watch')

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.palliativecareconsultation.ca/?q=mediawatch>

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/?s=ashpole>

Europe

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>

International

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)

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