Media Watch...

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

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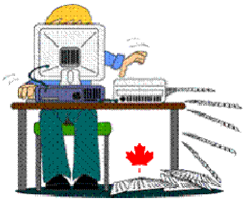


Compiled & Annotated by Barry R. Ashpole

U.K.'s National Association for Hospice at Home: 'Developing national standards for hospice-at-home services' (p.8), in *End of Life Journal.*

Canada

Caring for dying loved ones at home

The cost of dying

NOVA SCOTIA | *The Register/Advertiser* (Kentville) – 8 January 2013 – If the province would have paid for tube feeding supplements, a Wolfville woman says her husband could have died at home as he wished instead of in the hospital. Seana Collins lost her husband Balfour Collins less than two weeks before Christmas, following a 7½-year battle with medullary thyroid carcinoma. The oncologist had originally given him one to three years to live. Collins said the province needs a comprehensive palliative care program that removes the huge financial and emotional burdens from the shoulders of families caring for dying loved ones. The cost of the supplements is covered for patients in hospital, but not those staying at home. Collins said Balfour was in palliative care the last three years and the cost of the tube feeding supplements became an issue for them over the last six months. Most insurance providers don't cover the cost at all, although some will consider an appeal if a physician writes a letter of advocacy explaining the need for the nutritional therapy replacement. However, Collins didn't have any insurance coverage for the food supplements.http://www.novanewsnow.com/News/2013-01-08/article-3151145/The-cost-of-dying/1

Specialist Publications

Of related interest:

'Comparing the experiences of rural and urban family caregivers of the terminally ill' (p.13), in *Rural & Remote Health.*

'The fiscal impact of informal caregiving to home care recipients in Canada: How the intensity of care influences costs and benefits to government' (p.15), in *Social Science & Medicine.*

Cont.

Noted in Media Watch, 3 December 2012:

- NOVA SCOTIA | CBC News (Halifax) – 27 November 2012 – **'Nova Scotia palliative care program a 'rude awakening."** http://www.cbc.ca/news/health/story/2012/11/27/ns-palliative-care-food.html

Noted in Media Watch, 20 February 2012:

- NOVA SCOTIA | *Daily News* (Truro) – 15 February 2012 – **'Palliative home care patients eligible for free drug coverage.'** http://www.trurodaily.com/News/Local/2012-02-15/article-2896085/Palliative-home-care-patients-eligible-for-free-drug-coverage/1

Home, elder and end-of-life care

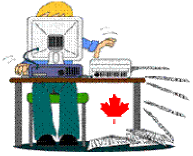
Ontario eyes changing health needs of aging population

ONTARIO | CBC News – 8 January 2013 – Ontario has been given a detailed prescription for addressing the health care challenges of its rapidly aging population, but the government is ready to act only on two of 169 recommendations it has been handed.[1] The province is taking a closer look at the implications of the growing ranks of Ontario seniors, a minority segment of the population that has costly health needs. As a result, the Ontario government is taking steps to ensure that all senior citizens have access to the health professionals who can provide them with the care they need in their advancing years – both to keep them healthy and out of hospital. According to government statistics, the 1.9 million seniors living in Ontario make up about 14.6% of the province's population. But they account for nearly half of all health-care spending. The provincial government believes the number of Ontario seniors may double within 20 years. http://www.cbc.ca/news/health/story/2013/01/08/ontario-seniors-health-care-needs.html

Extract from 'Living Longer, Living Well'

The Ministry of Health & Long-Term Care should continue to support its LHINs [Local Health Integrated Networks] in broadening the range of palliative care settings available in their regions, including within a patient's home, hospice, and institutional care settings as well.

1. 'Living Longer, Living Well,' January 2013. Submitted to Minister of Health & Long-Term Care and the Minister Responsible for Seniors on recommendations to inform a Seniors Strategy for Ontario. http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/docs/seniors_strategy.pdf



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

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

U.S.A.

Shrinking Medicare reimbursements

Hospice lays off dozens of employees

DELAWARE | Associated Press (Wilmington) – 10 January 2013 – Shrinking federal reimbursements have led the Delaware Hospice to lay off dozens of employees. The hospice's CEO, Susan Lloyd, said that the non-profit healthcare provider has let 52 workers go. She says the decision wasn't made lightly but is necessary to keep the hospice in operation. She says all departments in the 400-member staff will be affected by the job cuts, but that palliative care service won't be disrupted and that the hospice still plans to build a 24-bed facility in Pike Creek. She says part of the problem is that Medicare is no longer reimbursing hospice providers for certain services that had previously qualified. She says claims for Medicare reimbursement are under review. http://www.delmarvanow.com/article/20130110/NEWS01/301100089/?nclick_check=1

Specialist Publications

Of related interest:

'Effect of the Medicare face-to-face visit requirement on hospice utilization' (p.11), in *Journal of Palliative Medicine.*

A lesson in dying

As nurse lay dying, offering herself as instruction in caring

MASSACHUSETTS | *The New York Times* – 10 January 2013 – It was early November when Martha Keochareon called the nursing school at Holyoke Community College, her *alma mater*. She had a proposal, which she laid out in a voice mail message. "I have cancer," she said after introducing herself, "and I'm wondering if you'll need somebody to do a case study on, a hospice patient." Perhaps some nursing students "just want to feel what a tumor feels like," she went on. Or they could learn something about hospice care, which aims to help terminally ill people die comfortably at home. "Maybe you'll have some ambitious student that wants to do a project," Ms. Keochareon (pronounced CATCH-uron) said after leaving her phone number. "Thank you. Bye." Kelly Keane, a counselor at the college who received the message, was instantly intrigued. Holyoke's nursing students, like most, learn about cancer from textbooks. They get some experience with acutely ill patients during a rotation on the medical-surgical floor of a hospital. They practice their skills in the college's simulation lab on sophisticated mannequins that can "die" of cancer, heart attacks and other ailments. But Ms. Keochareon, 59, a 1993 graduate of Holyoke's nursing program, was offering students something rare: an opportunity not only to examine her, but also to ask anything they wanted about her experience with cancer and dying. http://www.nytimes.com/2013/01/11/us/fatally-ill-and-making-herself-the-lesson.html?pagewanted=all

National Institute of Medicine will recommend ways to improve end-of-life care

CALIFORNIA | *Marin Independent Journal* (Novato) – 10 January 2013 – In a national move that portends improvement of care for the dying, an expert panel assembled by the ... Institute of Medicine announced that it will recommend ways to improve end-of-life care in America. The Institute ... seeks changes in federal policy, financing and hospital practices that will bring care into line "with individual values and preferences to promote high-quality, cost-effective care at the end of life." The Institute's action comes amid heightened media attention on end-of-life care. http://www.marinij.com/ci_22348648/institute-medicine-will-recommend-ways-improve-end-life

Cont.

Of related interest:

- MICHIGAN | *The Holland Sentinel* – 9 January 2013 – **'New non-hospice palliative care clinic offered.'** Hospice of Holland is the first area facility to offer non-hospice palliative care to its patients. Palliative care benefits those who are not yet ready for hospice care, but need relief from their difficult symptoms like pain, discomfort, nausea, shortness of breath or depression. Those using non-hospice palliative care services are provided care by a team of specialists, including physicians, nurses and social workers. http://www.hollandsentinel.com/news/x1665859692/New-non-hospice-palliative-care-clinic-offered

Guide offers a blueprint for end-of-life conversation with youth

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES | National Institute of Mental Health – 7 January 2013 – 'Voicing My CHOICES' is the first guide designed to help adolescents and young adults express how they would like to be comforted, supported, and cared for in the course of serious illness, and how they would like to be remembered if they do not survive.[1] A paper in ... *Pediatrics* reported on a study in which young people with serious illnesses read and commented on pages from two existing advance care planning guides.[2] Their comments on specific questions shaped the content of 'Voicing My CHOICES.' http://www.nimh.nih.gov/science-news/2013/guide-offers-a-blueprint-for-end-of-life-conversation-with-youth.shtml

1. 'Voicing My CHOICES: A Planning Guide for Adolescents and Young Adults,' Aging with Dignity, October 2012. http://www.agingwithdignity.org/forms/voicingmychoices.pdf

2. 'Allowing adolescents and young adults to plan their end-of-life care,' *Pediatrics*, 8 October 2012. Adolescents and young adults ... want to be able to choose and record: 1) the kind of medical treatment they want and do not want; 2) how they would liked to be cared for: 3) information for their family and friends to know; and, 4) how they would like to be remembered. [Noted in Media Watch, 15 October 2012] http://pediatrics.aappublications.org/content/early/2012/10/02/peds.2012-0663.abstract

International

End-of-life care funding

20 of the 44 beds at Marymount [Hospice] are empty

IRELAND | *Evening Echo* (Cork) – 11 January 2013 – Sixteen months after opening its doors, just 24 patients are being cared for at Marymount Hospice, while a further 20 beds in the facility are lying empty. The €58 million facility, which is one of the most modern hospices in the world, is catering for just over half of the patients it was built for. This is despite the fact that the beds are in place, equipment is set up, and an entire floor in the building is waiting for patients. "We know the need is there and if the beds were open we could fill them straight away," said Kevin O'Dwyer, Chief Executive Officer at Marymount. Funding of €2.85 million is required annually to pay for the extra 45 posts needed to staff the 20 beds. However, due to budget cuts and despite exhaustive efforts by Marymount management and the HSE, that funding cannot be found. http://www.eveningecho.ie/2013/01/11/20-of-the-44-beds-at-marymount-are-empty/

Extract from *Evening Echo* article

The cost of a hospice bed is just €390 a day compared with €909 a day in acute hospitals. However, despite a 2002 Health Service Executive [HSE] needs assessment study, which recommended 44 hospice beds for the region, just 24 are operational. And following a 1.6% cut in the HSE palliative care budget for this year ... hopes are fading to have the beds opened this year.

Cont.

Noted in Media Watch, 19 September 2011:

- IRELAND | *Irish Times* – 19 September 2011 – **'€58m replacement care centre and hospital opens in Cork.'** A new palliative care centre and hospital was officially opened in Curraheen, Cork, following the transfer of patients from the facility's previous home at a site that was in operation for more than 100 years.http://www.irishtimes.com/newspaper/ireland/2011/0919/1224304355489.html

N.B. The Irish Hospice Foundation's *The strategic importance of palliative care within the Irish health service: Perspectives on future service delivery* examines palliative care from an all encompassing perspective which includes primary, secondary and tertiary care, patients of all ages and diagnoses and all care settings. Published January 2013. http://hospicefoundation.ie/wp-content/uploads/2013/01/The-strategic-importance-of-palliative-care-within-the-Irish-health-service-Perspectives-on-future-service-delivery.pdf

Debate on Liverpool Care Pathway

U.K. | BBC Democracy – 8 January 2013 – Conservative MP Glyn Davies led a debate on the Liverpool Care Pathway.[1] Liverpool University's Marie Curie Palliative Care Institute describes the care pathway as a form of "integrated care" used to "drive up sustained quality of the dying in the last hours and days of life." Its aim is to ensure that hospices' practices in caring for the dying are transferred to other clinical areas, so that wherever a person is dying they receive equally good care. In November 2012, the government announced an inquiry into allegations that thousands of people had been placed on the pathway without their knowledge or consent. Excerpt of debate: http://news.bbc.co.uk/democracylive/hi/house_of_lords/newsid_9729000/9729788.stm

1. Debate on The Liverpool Pathway (beginning with column 35WH), House of Commons Official Report, 8 January 2013. http://www.publications.parliament.uk/pa/cm201213/cmhansrd/chan92.pdf

Of related interest:

- U.K. | *The Argus* (Worthing, Sussex) – 11 January 2013 – **'Worthing care home is rapped over resuscitate forms.'** Two care home residents had notes on their files telling medical staff not to resuscitate – without any proof they agreed to it. The Care Quality Commission issued Longacre Care Home with a formal warning ordering bosses to make urgent improvements after the shocking find. http://www.theargus.co.uk/news/10144814.Care_home_is_rapped_over_resuscitate_forms/

- U.K. | *The Independent* – 8 January 2013 – **'Liverpool Care Pathway: A way of death worth fighting for?'** It has been denounced as 'euthanasia by the back door.' Now specialists in palliative medicine are defending its use. http://www.independent.co.uk/life-style/health-and-families/health-news/liverpool-care-pathway-a-way-of-death-worth-fighting-for-8443348.html

End-of-life care: 'Shortfall in NHS services'

U.K. (ENGLAND) | BBC News – 8 January 2013 – There is a shortage of specialist end-of-life care in England, causing unnecessary suffering, experts say. People dying with the most complex conditions, such as cancer, dementia and heart and liver failure often need support from a range of professionals. But a report – produced by end-of-life doctors and nurses – said many were going without the help they needed.[1] As well as being an inefficient use of NHS money, this could be causing greater distress at death, they said. Specialist end-of-life care requires teams of professionals, including doctors, nurses, social workers, psychologists and pharmacists to work together to help manage pain and disability in the final year of life and ensure patients are treated with dignity and compassion. http://www.bbc.co.uk/news/health-20948340

1. 'Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives,' December 2012. Developed in collaboration with: Association for Palliative Medicine of Great Britain & Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care, and the Palliative Care Section of the Royal Society of Medicine.http://www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf

It's not NHS workers who lack compassion, David Cameron – it's you

U.K. (ENGLAND) | *The Guardian* – 8 January 2013 – [Prime Minister] David Cameron recently underlined his government's belief that the NHS is not being compassionate enough to its patients when he announced that, starting next April, NHS staff are to be subjected to scrutiny by new "friends and family tests."[1] These will involve asking patients whether they would recommend the care they received at the hands of NHS services to their friends and family, a bit like a user review on Amazon... http://www.guardian.co.uk/commentisfree/2013/jan/08/nhs-david-cameron-compassion

1. 'Friends and family tests to expose poor care in NHS,' British Prime Minister's Office, 4 January 2013. http://www.number10.gov.uk/news/friends-and-family-test-nhs/

Noted in Media Watch, 24 December 2012:

- *NURSING IN PRACTICE* | Online – 18 December 2012 – **'NHS to implement Chief Nursing Officer vision of compassionate care.'** http://www.nursinginpractice.com/article/nhs-implement-cno-vision-compassionate-care

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IRELAND | *The Irish Times* (Dublin) – 11 January 2013 – **'Assisted suicide ban cannot be diluted even in 'harrowing' case of MS sufferer.'** The absolute ban on assisted suicide is fully justified under the Constitution to protect the most vulnerable in society and cannot be diluted even in the "harrowing" case of a woman terminally ill with multiple sclerosis, the High Court has ruled. However, the three-judge court said it was "sure" the Director of Public Prosecution would act in a "humane and sensitive" way in considering whether to prosecute any assisted suicide of Marie Fleming. Giving the court's judgment, president of the High Court Mr. Justice Nicholas Kearns ... said unravelling "even a thread" of the ban, by even a limited constititional finding in favour of Ms. Fleming, would, or might, "open a Pandora's box which thereafter would be impossible to close." http://www.irishtimes.com/newspaper/ireland/2013/0111/1224328672530.html

  Noted in Media Watch, 10 December 2012:

  - IRELAND | *Irish Central* – 5 December 2012 – **'Irish woman with terminal illness begins case for right-to-die lawsuit in Ireland.'** http://www.irishcentral.com/news/Irish-woman-with-terminal-illness-begins-case-for-right-to-die-lawsuit-in-Ireland-182161661.html

- POLAND | Polskie Radio (Warsaw) -10 January 2013 – **'Majority of Poles support euthanasia.'** A new poll indicates that the majority of Poles support the practice of euthanasia, suggesting that attitudes are shifting in the pre-dominantly Roman Catholic country. http://www.thenews.pl/1/9/Artykul/123716,Majority-of-Poles-support-euthanasia

- AUSTRALIA (SOUTH AUSTRALIA) | *The Advertiser* (Adelaide) – 8 January 2013 – **'Panel of doctors, lawyers, disability advocates and carers would oversee voluntary euthanasia.'** Independent MP Bob Such has drafted a revised voluntary euthanasia bill after his previous attempt was voted down in State Parliament mid-last year. The Ending Life With Dignity Bill 2013 would establish a board of about eight government-appointed members, including medical and legal practitioners and representatives of church groups, palliative carers, disability services and voluntary euthanasia advocates. http://www.news.com.au/national/panel-of-doctors-lawyers-disability-advocates-and-carers-would-oversee-voluntary-euthanasia/story-fndo4dzn-1226549878192

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

Patient and family involvement in decision making for management of cancer patients at a centre in Singapore

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 3 January 2013 – The practice of patient autonomy within the prevailing bioethical framework in the West appears increasingly at odds with the prominent influence of the family in medical decision making in the Asian culture. The actual extent of involvement of patient versus the family in the decision making process for cancer management in clinical practice is largely unknown in Asia. Involvement of patients and families [i.e., study participants] at first disclosure of diagnosis was noted in 61% and 64% of cases, respectively. In 12% of cases, the family requested withholding of the diagnosis from the patient; 86% of patients were involved in the initial treatment decisions, and their family was involved in 65% of cases. Only 9% of the 32 alert patients were consulted in end of life decisions. While most cancer patients are involved in the healthcare decision making process during the early phase, familial involvement gains prominence as disease progresses. http://spcare.bmj.com/content/early/2013/01/03/bmjspcare-2012-000323.abstract

Medical oncologists' perception of palliative care programs and the impact of name change to supportive care on communication with patients during the referral process. A qualitative study

PALLIATIVE & SUPPORTIVE CARE | Online – 11 January 2013 – Supportive care was perceived [by study participants] as an important time-saving application, and symptom control, transitioning to end-of-life care, family counseling, and improving patients' ability to tolerate cancer therapies were cited as important functions. Although most claimed that early referrals to the service are preferable, oncologists identified several challenges, related to the timing and communication with patients regarding the referral, as well as with the supportive care team after the referral was made. Whereas oncologists stated that the name change had no impact on their referral patterns, the majority supported it, as they perceived their patients preferred it. http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8814761&fulltextType=RA&fileId=S1478951512000685

Of related interest:

- *AMERICAN JOURNAL OF CRITICAL CARE*, 2013;22(1):4-6. **'Communicating and connecting with patients and their families.'** Critical illness presents unaccustomed challenges to patients and their families. Connection and communication have the potential to improve their experiences. http://ajcc.aacnjournals.org/content/22/1/4.short

- *BMC PALLIATIVE CARE* | Online – 11 January 2013 – **'Decision-making capacity and communication about care of older people during their last three months of life.'** Although relatives have positive experiences with ADs [advance directives], our study does not provide strong evidence that (proxy) ADs are very influential in the last phase of life. They can best be seen as a tool for advance care planning. http://www.biomedcentral.com/content/pdf/1472-684X-12-1.pdf

- *SUPPORTIVE CARE IN CANCER*, 2013;21(2):369-376. **'Using scenarios to explain life expectancy in advanced cancer: Attitudes of people with a cancer experience.'** More respondents [i.e., study participants] agreed that explaining three scenarios (versus median survival) would make sense, be helpful, convey hope, and reassure, while fewer respondents agreed that explaining three scenarios (versus median survival) would upset people. Most respondents agreed that each scenario should be presented: best case 89 %, worst case 82 %, and typical 92 %. For information about their own prognosis, 88 % preferred all three scenarios and 5 % a single estimate of the median. http://link.springer.com/article/10.1007/s00520-012-1526-4

U.K. National Association for Hospice at Home

Developing national standards for hospice-at-home services

END OF LIFE JOURNAL, 2013;3(1). There is minimal consensus regarding what constitutes hospice home care and hospice-at-home services. Such services have developed in an *ad-hoc* manner since the concept of hospice care at home was originally conceived by the Sisters of Charity at St Joseph's Hospice, Hackney, and then more formally developed by St Christopher's Hospice, London. Lack of uniformity means no single definition or model of hospice-at-home services exists. Therefore, many variations occur in the characteristics of service design and delivery across the U.K., Europe and internationally. This article describes the process undertaken by the National Association for Hospice at Home to develop a set of national standards for hospice-at-home services. http://endoflifejournal.stchristophers.org.uk/national-association-for-hospice-at-home/developing-national-standards-for-hospice-at-home

Talking about death in dementia

END OF LIFE JOURNAL, 2013;3(1). The author highlights how people with dementia often become depersonalised. As dementia progresses, carers may stop seeing the human being behind the condition, attributing all behaviour to pathology. However, despite behavioural change and loss of cognitive function, people who have dementia retain their sense of uniqueness and individuality. Although dementia may strip away memories and coherent verbal communication, it does not take away feelings, such as shame, embarrassment, pride, happiness, empathy, fear, anxiety, or the sense of being burdensome. http://endoflifejournal.stchristophers.org.uk/clinical-skills/communication-vignettes-talking-about-death-in-dementia

Cont. on next page

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 tool or change document.

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.

Of related interest:

- *BMC PSYCHIATRY* | Online – 10 January 2013 – **'Effectiveness and cost-effectiveness of an internet intervention for family caregivers of people with dementia: Design of a randomized controlled trial.'** http://www.biomedcentral.com/content/pdf/1471-244X-13-17.pdf

- *END OF LIFE JOURNAL*, 2013;3(1). **'What is dementia? Implications for caring at the end of life.'** A move away from polarised understandings of dementia is proposed in favour of a broader understanding that offers therapeutic potential to those with advanced dementia at the end of life. http://endoflifejournal.stchristophers.org.uk/clinical-practice-development/what-is-dementia

Noted in Media Watch, 12 November 2012:

- *DEMENTIA* | Online – 10 August 2012 – **'Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family...'** http://dem.sagepub.com/content/early/2012/08/08/1471301212450538.abstract

N.B. 'My Life Until the End: Dying Well with Dementia,' Alzheimer's Society. [Noted in Media Watch, 29 October 2012]: http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1537

Grief and bereavement

Meeting unmet needs? An initial evaluation of a groupwork approach to supporting children who are bereaved

GROUPWORK: AN INTERDISCIPLINARY JOURNAL FOR WORKING WITH GROUPS, 2012; 22(3):49-64. Support for children experiencing bereavement varies considerably across the U.K. depending on organisational values and resources, the specific population and the individual expertise and experience of professionals. This paper describes a groupwork approach to meeting the needs of this population. It was developed by a hospice in central Scotland in response to a lack of formal support identified by both professionals and families within the community. It uses the 'Seasons for Growth' loss and change education programme as a method of groupwork intervention.[1] The paper discusses the initial evaluation of the groupwork service from when it was established in September 2007 to January 2010. It outlines the background to setting up the service, the sources and reasons for referral and the evaluation process and findings. Implications for group intervention with children who are bereaved are discussed in the conclusion. http://www.ingentaconnect.com/content/wab/gijwg/2012/00000022/00000003/art00004

1. 'Seasons for Growth' is a loss and grief peer-group education programme for young people aged 6-18 years and adults. It was first delivered in 1996 and is well established in Australia, New Zealand, Ireland and the U.K. http://seasonsforgrowth.co.uk/

Of related interest:

- *END OF LIFE JOURNAL*, 2013;3(1). **'Understanding factors that influence the grieving process.'** In light of evidence from bereavement research over the last two decades, previous paradigms regarding grief and loss are changing, which has important implications for professionals, including nurses, who work in end-of-life care. http://endoflifejournal.stchristophers.org.uk/clinical-practice-development/understanding-factors-that-influence-the-grieving-process

- *JOURNAL OF THE ASSOCIATION OF NURSES IN AIDS CARE*, 2013;24(1):S61-S71. **'Grief in the context of HIV: Recommendations for practice.'** This report summarizes evidence from the literature and clinical practice to support recommendations for the practice of nurses caring for persons with HIV-associated grief; recommended strategies are illustrated through an exemplar case study. http://www.nursesinaidscarejournal.org/article/S1055-3290(12)00246-4/abstract

Palliative care in India: Current progress and future needs

INDIAN JOURNAL OF PALLIATIVE CARE, 2012;18(3):149-154. Despite its limited coverage, palliative care has been present in India for about twenty years. Obstacles in the growth of palliative care in India are too many and not only include factors like population density, poverty, geographical diversity, restrictive policies regarding opioid prescription, workforce development at base level, but also limited national palliative care policy and lack of institutional interest in palliative care. Nonetheless we have reasons to be proud in that we have overcome several hurdles and last two decades have seen palpable changes in the mindset of health care providers and policy makers with respect to need of palliative care in India. Systematic and continuous education for medical staff is mandatory, and a major break-through for achieving this purpose would be to increase the number of courses and faculties in palliative medicine at most universities. http://www.jpalliativecare.com/article.asp?issn=0973-1075;year=2012;volume=18;issue=3;spage=149;epage=154;aulast=Khosla;type=0

N.B. *Indian Journal of Palliative Care* contents page: http://www.jpalliativecare.com/currentissue.asp?sabs=n

Of related interest:

- *INDIAN JOURNAL OF PSYCHIATRY*, 2013;55(6): 293-298. **'End-of-life care: Indian perspective.'** This article studies the core issues of developing palliative care in Indian setting keeping in mind the ethical, spiritual and legal issues. http://www.indianjpsychiatry.org/article.asp?issn=0019-5545;year=2013;volume=55;issue=6;spage=293;epage=298;aulast=Sharma

Education

Empowering nursing assistants to improve end-of-life care

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2013;15(1):24-32. Nursing assistants are integral to palliative care and are often the most deeply involved and consistent care providers to dying patients. Yet the contributions of nursing assistants are often unrecognized and underappreciated. They are frequently marginalized when it comes to professional education activities, particularly in the acute care setting. This article describes an educational initiative based on the Hospice & Palliative Nursing Association nursing assistant core curriculum. The results of this pilot study showed that a daylong conference on end-of-life care was associated with improved measures of knowledge, attitudes about care of the dying, and awareness of ethical issues. Interesting points of discussion concerned the points of tension identified by nursing assistants in the care of dying patients, the need for ongoing support for these staff members, and the practical issues of how to best educate and integrate nursing assistants into the palliative care team. http://journals.lww.com/jhpn/Abstract/2013/02000/Empowering_Nursing_Assistants_to_Improve.6.aspx

Of related interest:

- *BMC MEDICAL EDUCATION* | Online – 4 January 2013 – **'Evaluating an evidence-based curriculum in undergraduate palliative care education: Piloting a phase II exploratory trial for a complex intervention.'** Debates are ongoing as how Undergraduate Palliative Care Education should be taught and how knowledge and skills should be assessed. The development process of early curricula in the U.S. and U.K. has led to a plethora of diverse curricula which seem to be partly ineffective in improving the care for the seriously ill and dying offered by newly qualified doctors, as is demonstrated in controlled evaluations. http://www.biomedcentral.com/content/pdf/1472-6920-13-1.pdf

- *DIALOGUE* (Ontario medical Association), 2012;8(4). **'Getting an education in palliative care.'** http://www.cpso.on.ca/uploadedFiles/policies/publications/dialoguearchives/dialogueissues/end-of-life_education.pdf

Information management and quality of palliative care in general practices: Secondary analysis of a U.K. study

JOURNAL OF INFORMATION SCIENCE | Online – 4 January 2013 – A recent national U.K. survey of palliative care within general practices concluded practices that utilized recognized initiatives to promote palliative care demonstrated better clinical care and higher perceived quality of palliative care. This paper reports on secondary analyses from that survey to investigate the management of information related to palliative care within practices. Relatively high levels of information provision to families and carers were reported, over two-thirds of practices reported having unified records for palliative care patients, and over 90% of practices reported having a cancer/palliative care register that was fully or mostly operational. Larger practices, those using the Gold Standards Framework[1] and practices using unified record keeping for palliative care, were independently more likely to give information to families and carers and were more likely to have a mostly or fully operational palliative care register. When testing for the relationship between measures of the structures and processes of information management and the perceived quality of care, as an outcome, within the practices, practices with a fully operational palliative care register and practices that had higher scores on the record-keeping scale were more likely to rate the quality of their palliative care as very good.http://jis.sagepub.com/content/early/2013/01/04/0165551512470045.abstract

Between beneficence and justice: The ethics of stewardship in medicine

JOURNAL OF MEDICINE & PHILOSOPHY | Online – 5 January 2013 – This article presents a critical analysis of the notion of stewardship, which shows that it has an important and distinctive place in medical ethics. It claims that stewardship in medicine concerns the responsible use of a society's medical resources and it discusses the extent to which medical professionals are the proper stewards of these resources. The article argues that the duty of stewardship is best understood as a duty that applies in a space between the obligations of health care providers to provide beneficent care to their patients on the one hand and the obligations of citizens to bring about and support a just health care system on the other. Seen with clear eyes, stewardship in medicine is neither a consequence of beneficent medical care nor a substitute for justice. http://jmp.oxfordjournals.org/content/early/2013/01/04/jmp.jhs058.abstract

1. National Gold Standards Framework website: http://www.goldstandardsframework.org.uk/

Dignifying death and the morality of elective ventilation

JOURNAL OF MEDICAL ETHICS | Online – 8 January 2013 – In this paper the authors defend that elective ventilation (EV), even if conceived as the instrument to maximise the chances of organ recovery, is mainly the means to provide the patient who is dying with a dignified death in several ways, one of them being the possibility of becoming an organ donor. Because EV does not harm the patient and permits the medical team a better assessment of the patient's clinical trajectory and a better management of the dying process by the family, EV does not violate the principle of non-beneficence nor the principle of autonomy if we restrict the initiation of EV to those cases in which it is not known what the previous wishes of the patient were as regards to his or her care at the end of life. http://jme.bmj.com/content/early/2013/01/08/medethics-2012-100995.abstract

Effect of the Medicare face-to-face visit requirement on hospice utilization

JOURNAL OF PALLIATIVE MEDICINE | Online – 11 January 2013 – Although many patients enter hospice close to death, some enroll for more than six months. In 2011 the U.S. Centers for Medicare and Medicaid Services (CMS) required that these long-stay patients receive a face-to-face visit by a physician or nurse practitioner to ensure that they continue to meet eligibility criteria. The face-to-face requirement [however] may decrease hospice discharges, contrary to its intention. http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0349

The nature of, and reasons for, 'inappropriate' hospitalisations among patients with palliative care needs: A qualitative exploration of the views of generalist palliative care providers

PALLIATIVE MEDICINE | Online – 7 January 2013 – The majority of [study] participants discussed 'appropriateness' in relation to their own understanding of a good death, which typically involved care being delivered in a 'homely' environment, from known people. Differing attitudes among cultural groups were also evident. The following reasons for inappropriate admissions were identified: family carers being unable to cope, the 'rescue culture' of modern medicine, the financing and availability of community services and practice within aged residential care. On the basis of their findings, the authors recommend a shift to the term 'potentially avoidable' admission rather than 'inappropriate admission.' They identify an urgent need for debate regarding the role of the acute hospital within a palliative care context. Interventions to reduce hospital admissions within this population must target societal understandings of death and dying within the context of medicalisation, as well as take into account cultural and ethnic diversity in attitudes, if they are to be successful. http://pmj.sagepub.com/content/early/2013/01/04/0269216312469263.abstract

Media Watch Online

Asia

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

Australia

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: http://www1.petermac.org/apli/links.htm (Scroll down to 'Links,' then to 'Media Watch')

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

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

End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives

PALLIATIVE MEDICINE | Online – 7 January 2013 – 'Deciding for someone else' describes the context in which patient representatives [i.e., study participants] took end-of-life decisions. The patient representatives felt highly responsible for the outcomes. They had not involved the patients in the end-of-life decision-making process, nor any professionals other than the doctor. 'Motives' and 'Support' were connected to the core category of 'Deciding for someone else.' 'Motives' refers to the patient representatives' ideas about quality of life, prevention from suffering, patients who cannot understand the burden of interventions and emotional reasons reported by patient representatives. 'Support' refers to the support that patient representatives wanted the doctors to give to them in the decision-making process. From the perspective of the patient representatives, the process of end-of-life decision-making can be improved by ensuring clear roles and an explicit description of the tasks and responsibilities of all participants. Regular discussion between everyone involved including people with intellectual disabilities themselves can improve knowledge about each other's motives for end-of-decisions and can clarify expectations towards each other. http://pmj.sagepub.com/content/early/2013/01/04/0269216312468932.abstract

Noted in Media Watch, 26 November 2012:

- *AMERICAN JOURNAL ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES*, 2012;117(6): 509-532. **'Unique and universal barriers: Hospice care for aging adults with intellectual disability.'** http://www.aaiddjournals.org/doi/abs/10.1352/1944-7558-117.6.509

Noted in Media Watch, 1 October 2012:

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES* | Online – 21 September 2012 – **'End-of-life care and dying: Issues raised by staff supporting older people with intellectual disability in community...'** http://onlinelibrary.wiley.com/doi/10.1111/jar.12000/abstract

Comparing the experiences of rural and urban family caregivers of the terminally ill

RURAL & REMOTE HEALTH | Online – 7 January 2013 – Previous work has identified consistent themes around end-of-life care, including caregiver burden in providing care, the importance of informal care networks and barriers imposed by geography. Despite these well-known barriers, few studies have explored the experience of palliative care in rural settings. Rural and urban caregivers [i.e., study participants] were providing care to recipients with similar functional status; the majority of care recipients were either capable of all self-care or experiencing some limitation in self-care. No group differences were observed for caregiver perceived burden: both rural and urban caregivers reported low levels of burden. Urban and rural caregivers also reported similarly high levels of social support. Although caregivers across both settings reported using a comparable number of services, the types of services used differed. Rural caregivers reported greater use of family physicians, emergency room visits and pharmacy services, while urban caregivers reported greater use of caregiver respite services. Results ... suggest that while there are commonalities to the caregiving experience regardless of setting, key differences also exist. Location is a factor to be considered when implementing palliative care programs and services.http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=2250

Feelings of guilt – experiences of next of kin in end-of-life care

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2013;15(1):33-40. The situation of being next of kin in end-of-life care is complex and demanding, something that health professionals are and should be aware of. Acknowledgement of experiences of guilt can help the next of kin in their adaptation to the end-of-life situation as a whole and maybe also give useful tools to support next of kin through bereavement. http://journals.lww.com/jhpn/Abstract/2013/02000/Feelings_of_Guilt_Experiences_of_Next_of_Kin_in.7.aspx

Cont.

Noted in Media Watch, 26 November 2012:

- *SUPPORTIVE CARE IN CANCER* | Online – 19 November 2012 – **'Improving access to specialist multidisciplinary palliative care consultation for rural cancer patients by videoconferencing...'** http://link.springer.com/content/pdf/10.1007%2Fs00520-012-1649-7

Noted in Media Watch, 1 October 2012:

JOURNAL OF FAMILY NURSING | Online – 24 September 2012 – **'Supporting rural family palliative caregivers.'** http://jfn.sagepub.com/content/early/2012/09/23/1074840712462065.abstract

Noted in Media Watch, 30 July 2012:

- *CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 15 July 2012 – **'End-of-life care in rural areas: What is different?'** http://www.ncbi.nlm.nih.gov/pubmed/22801467

Noted in Media Watch, 2 July 2012:

- *GLOBAL JOURNAL OF HEALTH SCIENCE*, 2012;4(5):1-13. **'Canadian rural-urban differences in end-of-life care...'** http://www.ccsenet.org/journal/index.php/gjhs/article/viewFile/17521/12109

N.B. See Media Watch, 30 April 2012 (p.8-9), for a listing of additional articles, reports, etc., on the provision and delivery of end-of-life care in the rural setting.

Literature review

Interventions concerning competence building in community palliative care services

SCANDINAVIAN JOURNAL OF CARING SCIENCES | Online – 4 January 2013 – Studies establish that many incurably ill people would prefer to die at home, whether their final home is their own home or a nursing home. Experience shows that the professionals in palliative care at the basis level need to increase their competences. The purpose of this literature review is to examine experiences with interventions regarding the development of competencies within community palliative care services – in other words, at the individual work places. The review of the literature identified fifteen publications which dealt with interventions regarding education and competence building. The publications represent individual studies, only two of which were controlled. All conclude that competence building has a positive effect according to the professionals. It is unknown whether or how patients and relatives feel a positive effect from the interventions just as it is unknown how the development of competencies has actually led to a more developed practice. http://onlinelibrary.wiley.com/doi/10.1111/scs.12020/abstract;jsessionid=BC7091D4BCD5863FB3EA5317DEA078E6.d03t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2012;44(6):797-809. **'Demonstration of a sustainable community-based model of care across the palliative care continuum.'** With health care reform promoting integration of care across settings, outpatient palliative care will gain importance in the health care continuum. Process changes can help reduce financial losses that currently impede outpatient palliative care programs. http://www.jpsmjournal.com/article/S0885-3924(12)00181-9/abstract

The fiscal impact of informal caregiving to home care recipients in Canada: How the intensity of care influences costs and benefits to government

SOCIAL SCIENCE & MEDICINE | Online – 5 January 2013 – The objective of this study was to estimate the annual costs and consequences of unpaid caregiving by Canadians from a government perspective. The authors estimated these costs both at the individual and population levels for caregivers aged 45 and older. They conducted a cost-benefit analysis where they considered the costs of unpaid caregiving to be potential losses in income tax revenues and changes in social assistance payments and the potential benefit of reduced paid care expenditures. At the lowest intensities of caregiving, there was a net benefit to government from caregiving, at both the individual and population levels. At the population level, the net benefit to government was estimated to be $4.4 billion for caregivers providing less than five hours of weekly care. At the highest intensity of caregiving, there was a net cost to government of $641 million. The authors found that the factor with the greatest impact on cost was the probability of labour force participation. http://www.sciencedirect.com/science/article/pii/S0277953612008386

Of related interest:

- *SCANDINAVIAN JOURNAL OF CARING SCIENCES* | Online – 4 January 2013 – **'The needs of informal caregivers of elderly people living at home: An integrative review.'** This integrative review offers important insight into the needs of informal caregivers, specifically for the elderly. http://onlinelibrary.wiley.com/doi/10.1111/scs.12019/abstract

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- GOVERNMENT OF THE NETHERLANDS | **'Second evaluation [of the] Act Termination of Life on Request & Assisted Suicide'** – Accessed 7 January 2013 – In this report, the results are presented of the second evaluation of the efficacy and side-effects of the Act, ten years after its enforcement. The authors have studied trends in end-of-life decision-making practices, developments in the interpretation and conceptualization of the legal requirements, and potential problems and complexities of the review system. The study consists of a legal study, a study of clinical practices, and a study of the review committees. http://www.zonmw.nl/uploads/tx_vipublicaties/wtl2_v1-0-web.pdf

  N.B. English language summary of report begins on p.19.

- *MCGILL JOURNAL OF LAW & HEALTH*, 2012;6(2):113-172. **'Prosecutorial discretion in assisted dying in Canada: A proposal for charging guidelines.'** An Expert Panel of the Royal Society of Canada and a Select Committee of the Québec National Assembly both recently recommended the issuance of permissive guidelines for the exercise of prosecutorial discretion on voluntary euthanasia and assisted suicide and "medical aid in dying" respectively.[1,2] It seems timely, therefore, to propose a set of offence specific guidelines for how prosecutorial discretion should be exercised in cases of voluntary euthanasia and assisted suicide in Canadian provinces and territories. http://mjlh.mcgill.ca/pdfs/vol6-2/MJLH%20Vol%20VI.%20No.%202%20-%20Downie&White.pdf

  1. *Royal Society of Canada Expert Panel: End of Life Decision Making*, November 2011. [Noted in Media Watch, 21 November 2011] http://www.rscsrc.ca/documents/RSCEndofLifeReport2011_EN_Formatted_FINAL.pdf

  2. *La Commission spéciale sur la question de mourir dans la dignité dépose son rapport*, Select Committee of the Québec National Assembly, March 2012. [Noted in Media Watch, 26 March 2012] http://www.worldrtd.net/sites/default/files/newsfiles/Quebec_Report%20in%20English.pdf

Worth Repeating

Redefining the "planning" in advance care planning: Preparing for end-of-life decision making

ANNALS OF INTERNAL MEDICINE, 2010;153(4):256-261. The traditional objective of advance care planning has been to have patients make treatment decisions in advance in an attempt to provide care consistent with their goals. The authors argue that the objective for advance care planning ought to be the preparation of patients and surrogates to participate with clinicians in making the best possible in-the-moment medical decisions. They provide practical steps for clinicians to help patients and surrogate decision makers achieve this objective in the outpatient setting. Preparation for in-the-moment decision making shifts the focus from having patients make premature decisions based on incomplete information to preparing patients and their surrogates for the types of decisions and conflicts they may encounter when they do have to engage in in-the-moment decision making. This approach does not preclude the completion of advance directives, but acknowledges that they are but one piece of information to be used at the time of decision making. http://annals.org/article.aspx?articleid=745978

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