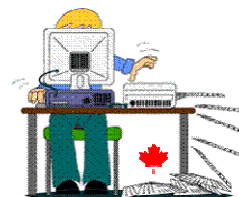


Media Watch...

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

Problematic nature of professional education in end-of-life care: Scroll down to [Specialist Publications](#) and 'Learning and teaching palliative care: Can we do better?' (p.11) in *Journal of Palliative Care & Medicine*.

U.S.A.

For some, at-home funerals offer last chance for connection

MASSACHUSETTS | WGBH News (Boston) – 4 December 2013 – The movement toward at-home births has been gaining momentum for years, but what about at-home funerals? There's a small but growing movement to educate people that they can take care of a loved one at home after death, instead of using a funeral home. <http://wgbhnews.org/post/some-home-funerals-offer-last-chance-connection>

Specialist Publications

'The industry take-over of home birth and death' (p.11), in *Journal of Clinical Ethics*.

Terminally ill Iowa inmate gets parole for hospice

IOWA | *The Washington Post* – 3 December 2013 – A dying Iowa inmate who was 15 when she entered prison will spend her final days in a hospice facility, a state board ruled in granting her unprecedented parole. The Iowa Parole Board's decision for Kristina Fetters, 33, means she is the first inmate in the state sentenced to life in prison as a juvenile to be released after a landmark U.S. Supreme Court ruling last year.¹ http://www.washingtonpost.com/national/health-science/terminally-ill-iowa-inmate-gets-parole-for-hospice/2013/12/03/67cb79ec-5c48-11e3-8d24-31c016b976b2_story.html

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Quotable Quotes

What counts in life is not the mere fact that we have lived. It is what difference we have made to the lives of others that will determine the significance of the life we lead.

Nelson Rolihlahla Mandela (1918-2013)

1. 'Supreme Court rules mandatory juvenile life without parole cruel and unusual,' *The Los Angeles Times*, 25 June 2012. In a five-to-four decision, the high court struck down as cruel and unusual punishment the laws in about 28 states that mandated a life term for murderers, including those under age eighteen. <http://articles.latimes.com/2012/jun/25/news/la-pn-supreme-court-rules-juvenile-life-without-parole-cruel-and-unusual-20120625>

When palliative care is the best care

KAISER HEALTH NEWS | Online – 3 December 2013 – More than two-thirds of hospitals with more than 50 beds offer palliative care, up from 25% in 2000, according to the Center to Advance Palliative Care at Mount Sinai School of Medicine. Washington is a leader in the field; more than 80% of hospitals have such programs.¹ The increase in popularity is in part due to the growing number of people with chronic illness who may not be ready for hospice. Medicare only pays for hospice benefits if patients have six months or less to live and agree to forgo treatment that prolongs life. "You shouldn't be days or weeks from death to have your symptoms managed and pain taken care of," said R. Sean Morrison, director of the National Palliative Care Research Center. But some doctors are resistant to palliative care because they believe it pushes patients away from medical treatment that could help them fight their illnesses. Even the idea of patients planning ahead and making decisions about their care has caused controversy. A provision that would have paid doctors for having discussions about living wills with their patients was taken out of the Affordable Care Act after conservatives raised

concerns over "death panels." An Oregon congressman is trying to revive that discussion with a similar proposal. Regardless of what happens with the legislation, experts said palliative care programs will continue to grow as baby boomers age and as hospitals look for ways to reduce costs and increase value under the nation's health care law. <http://www.kaiserhealthnews.org/Stories/2013/December/03/palliative-care-for-seriously-ill.aspx>

Specialist Publications

'Mandating advance directives [in the U.S.]' (p.13), in *Aging Clinical & Experimental Research*.

'American Medical Association guidelines call for prompt, thorough communication after unexpected death' (p.11), in *AMA News*.

'Centers for Medicare & Medicaid Services issues new surveyor guidance on Initiating CPR in nursing homes and facility cardiopulmonary resuscitation/do not resuscitate policies' (p.12), in *The National Law Review*.

1. *Tracking Improvement in the Care of Chronically Ill Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life*, June 2013. [Noted in Media Watch, 17 June 2013, #310 (p.4)] http://www.dartmouthatlas.org/downloads/reports/EOL_brief_061213.pdf

Of related interest:

- *THE NEW YORK TIMES* | Online – 2 December 2013 – '**Palliative care, the treatment that respects pain.**' The benefits of palliative care include fewer trips to the emergency room or hospital, lower medical costs, improved ability to function and enjoy life and ... prolonged survival for the terminally ill. These virtues far outweigh what it would cost to make this service universally available in hospitals, nursing homes, clinics, assisted living facilities and patient's homes. But there are two major stumbling blocks, one of which patients and their families can help to eliminate. First is the widespread misunderstanding of palliative care by the public and medical profession: both wrongly equate it with hospice and end-of-life care. The second obstacle to making palliative care more available is a shortage of doctors trained in it.¹ <http://well.blogs.nytimes.com/2013/12/02/palliative-care-the-treatment-that-respects-pain/?ref=health&r=0>

1. 'More doctors sought to meet hospice and palliative care demands,' *American Medical News*, 21 August 2012. From 8,000 to 10,000 physician specialists are needed to meet demands in hospice and palliative care programs nationwide. [Noted in Media Watch, 27 August 2012, #268 (p.7)] <http://www.ama-assn.org/amednews/2012/08/20/prsc0821.htm>

International

Funding end-of-life care in the U.K.

Loan will "transform end-of-life care" in North West Surrey

U.K. (ENGLAND) | 96.4 Eagle Radio News (Guildford, Surrey) – 4 December 2013 – It is claimed a new loan could transform end of life care in North West Surrey. £6 million has been secured by the Woking and Sam Beare Hospices. The loan from Woking Borough Council will be used to make big changes to the hospices. It will see a site in Woking developed into a state-of-the-art inpatient facility, with 20 beds. The site in Weybridge will focus on community and day care. An extensive review has shown the hospices are currently working at capacity, serving over 1,000 patients. Pressure is set to increase due to an ageing population. <http://www.964eagle.co.uk/news/local-news/1144781/loan-will-transform-end-of-life-care-in-north-west-surrey/>

Judge rules that man in vegetative state should not be resuscitated if his condition deteriorates

U.K. (ENGLAND) | *The Independent* (London) – 4 December 2013 – A man in a vegetative state should not be resuscitated if his condition deteriorates, a High Court judge has ruled. A 78-year-old man [identified only as SM] from the north of England has been in a vegetative or – at best – minimally conscious state since May. Despite his advanced ill health, his family said that in the event of a heart attack, they would prefer him to be kept alive. Handing down his judgement, Justice Mostyn said it was "perfectly clear to me that it would not be in SM's best interests" to undergo resuscitation in the event of a cardiac arrest. He said: "Should this crisis eventuate it is clear there's a significant risk of further mental deterioration of SM, even from the low level he is at at the moment." The judge also ordered that SM underwent a thorough test of his mental state and was fitted with a less intrusive feeding tube. <http://www.independent.co.uk/life-style/health-and-families/health-news/judge-rules-that-man-in-vegetative-state-should-not-be-resuscitated-if-his-condition-deteriorates-8983801.html>

Specialist Publications

'Dying in two acute hospitals: Would usual care meet Australian national clinical standards?' (p.6), in *Australian Health Review*.

'The judgment of the High Court [of England] in two right-to-die cases' (p.14), in *End of Life Journal*.

'[U.K.] Palliative Care Funding Review: Implications for family carers' (p.10), in *End of Life Journal*.

'Population ageing and healthcare expenditure Projections [in Scotland]: New evidence from a time to death approach' (p.10), in *European Journal of Health Economics*.



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

Liverpool Care Pathway being "rebranded" not axed

U.K. (ENGLAND & WALES) | *The Daily Telegraph* (London) – 1 December 2013 – The discredited Liverpool Care Pathway is to be "rebranded" rather than abolished, senior doctors have said. In July ministers said the end-of-life protocols would be axed, after a damning independent review uncovered frequent and "heartbreaking" cases of patients being denied water and left desperately sucking at sponges used to moisten their mouths. Instead, every patient would receive individual end-of-life care plans, following the review led by Baroness Julia Neuberger.¹ However, doctors who led criticism of the pathway say new draft guidance, seen by *The Daily Telegraph*, outlining a replacement scheme will perpetuate many of its worst practices, allowing patients to suffer days of dehydration, or to be sedated, leaving them unable to even ask for food or drink. Professor Patrick Pullicino, a consultant neurologist ... said the new plan "lacks essential key components of the Neuberger report and perpetuates errors that were central to the dysfunction of the pathway." <http://www.telegraph.co.uk/health/healthnews/10487109/Liverpool-Care-Pathway-being-rebranded-not-axed.html>

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

Noted in Media Watch, 25 November 2013, #333 (p.15):

- *COCHRANE DATABASE OF SYSTEMATIC REVIEWS* | Online – 18 November 2013 – '**End-of-life care pathways for improving outcomes in caring for the dying.**' With sustained concerns about the safety of the pathway implementation and the lack of available evidence on important patient and relative outcomes, recommendations for the use of end-of-life pathways in caring for the dying cannot be made. No new studies met criteria for inclusion in the review update. <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD008006.pub3/abstract>
 1. The original review identified 920 titles. The updated search found 2042 potentially relevant titles (including the original 920), but no additional studies met criteria for inclusion in the review update.
- *PALLIATIVE MEDICINE* | In Press – Accessed 19 November 2013 – '**Do palliative care health professionals settle for low level evidence?**' The findings of the recent independent review of the U.K. Liverpool Care Pathway (LCP), following substantial concerns raised by members of the public and health professionals found that the implementation of the LCP is often associated with poor care. <http://eprints.qut.edu.au/64198/>

Of related interest:

- U.K. (ENGLAND & WALES) | *The Daily Telegraph* (London) – 1 December 2013 – '**More than a thousand care home residents die thirsty.**' Elderly and vulnerable patients were left without enough water despite being under the supervision of trained staff in homes in England & Wales. The Coalition [i.e., government] has failed to improve the situation, with more people dying while dehydrated last year than when [Prime Minister] David Cameron took office, although the total was lower than the 2006 peak. Charities called for an overhaul in social care, saying that the general public would be outraged if animals were treated in the same way. <http://www.telegraph.co.uk/health/healthnews/10487305/More-than-a-thousand-care-home-residents-die-thirsty.html>

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[Media Watch Online](#)

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.7.

End-of-life care in Korea

Guidelines detail end-of-life terms

KOREA | *JoongAng Daily* (Seoul) – 29 November 2013 – Following years of public discussion on how to ensure terminally ill patients live their last moments with dignity, the Ministry of Health & Welfare unveiled the first draft of its "death with dignity" guidelines. The government is seeking to allow terminally ill patients to forgo life-sustaining medical care in the event that they sign an "advanced directive," which indicates that treatment will be withdrawn when there is no chance of recovery. The guidelines also said that even without an advanced directive, life-sustaining procedures can be stopped if more than two members of the family confirm that the patient preferred to waive his or her end-of-life treatment. In such a case, the consent of two doctors would also be necessary. <http://koreajoongangdaily.joins.com/news/article/article.aspx?aid=2981235>

Noted in Media Watch, 14 October 2013, #327 (p.9):

- *CRITICAL CARE* | Online – 4 October 2013 – '**Survey of controversial issues of end-of-life treatment decisions in Korea: Similarities and discrepancies between healthcare professionals and the general public.**' Over 50% [of survey respondents] thought that end of life treatment decisions should be made through discussions between the physician and the patient's family. For conflict resolution, 75% of Koreans not working in healthcare preferred direct settlement between the medical staff and the patient's family, while 55% of healthcare professionals preferred the hospital ethics committee. <http://ccforum.com/content/pdf/cc13042.pdf>
- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2013;15(7):410-418. '**Facilitators and barriers to use of advance directives in Korea.**' Seven barriers emerged [in this study]: negative attitudes, lack of a legal system, Korean Confucian belief, limited support, professional incompetence and advances in medical therapy. Public and professional education is believed to be critical... A legal model compatible with Korean culture is also needed. http://journals.lww.com/jhpn/Abstract/2013/10000/Facilitators_and_Barriers_to_Use_of_Advan ce.10.aspx

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

Discordance in HIV-positive patient and health care provider perspectives on death, dying, and end-of-life care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 6 December 2013 – Patients and providers [i.e., study participants] demonstrated profound differences in their perspectives on patient empowerment and attributions of control related to disease progression, imminence of death, and EOLC [end-of-life care] decision making. Notably, patients described fears related to life-extending interventions that generally went unaddressed within the clinical context. <http://ajh.sagepub.com/content/early/2013/12/06/1049909113515068.abstract>

What parents want from doctors in end-of-life decision-making for children

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 5 December 2013 – There has been little information on how parents see the role of doctors in end-of-life decision-making for children. Parents [i.e., study participants] reported varying roles taken by doctors: being the provider of information without opinion; giving information and advice as to the decision that should be taken; and, seemingly being the decision maker for the child. The majority of parents found that their child's doctor enabled them to be the ultimate decision maker for their child, which was what they very clearly wanted to be, and consequently enabled them to exercise their parental autonomy. Parents found it problematic when doctors took over decision-making. A less frequently reported, yet significant role for doctors was to affirm decisions after they had been made by parents. <http://adc.bmj.com/content/early/2013/12/05/archdischild-2013-304249.abstract>

Cont.

Noted in Media Watch, 1 July 2013, #312 (p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 June 2013 – **“To be a phenomenal doctor you have to be the whole package”: Physicians' interpersonal behaviors during difficult conversations in pediatrics.** Eleven interpersonal behaviors were identified as important by parents [i.e., study participants]. The majority identified empathy in physicians as critical. Availability, treating the child as an individual, and respecting the parent's knowledge of the child were mentioned by almost half of parents. Themes also considered important ... were allowing room for hope, the importance of body language, thoroughness, going beyond the call of duty, accountability, willingness to accept being questioned, and attention to the suffering of the child. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0103>

Noted in Media Watch, 22 October 2013, #276 (p.9):

- *PROGRESS IN PALLIATIVE CARE* | Online – 15 October 2012 – **'The child's voice in pediatric palliative and end-of-life care.'** Although much is asked clinically and emotionally of children and adolescents receiving treatment for a life-threatening illness, they are not routinely asked how they experience the treatment that is intended to save or prolong their lives. The absence of the child's voice in palliative and end-of-life care jeopardizes best care efforts. <http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000035>

Dying in two acute hospitals: Would usual care meet Australian national clinical standards?

AUSTRALIAN HEALTH REVIEW | Online – 27 November 2013 – The Australian Commission for Quality & Safety in Health (ACQSH) has articulated eight clinical standards with the aim of improving the consistency of delivery of quality health care. Currently, the majority of Australians die in acute hospitals. But despite this, no agreed standard of care exists to define what is the minimum standard of care people should accept in the final hours to days of life. As a result, there is limited capacity to conduct audits that focus on the gap between current care and recommended care. There is however, accumulating evidence in the end of life literature to define which aspects of care are considered important to people facing imminent death. Such themes offer standards against which to conduct audits. This is apt given the national recommendation that health care should be delivered in the context of considering people's wishes while always treating people with dignity and respect. This work describes a gap analysis undertaken to explore if issues defined by

people facing imminent death as important would have been addressed by usual care of the dying in general hospital ward. The specific issues examined included the documentation that was available to define that this person was likely to die soon and how engaged the person dying seemed to be in discussions, how the person was monitored to ensure distressing symptoms were addressed when necessary and what investigations were considered necessary after the time the person was identified as dying. http://www.publish.csiro.au/view/journals/dsp_journals_pip_abstract_Scholar1.cfm?nid=270&pip=AH13174

Extract from *Australian Health Review* article

This review highlights that usual care would not meet people's wishes suggesting that care of the dying would not meet the ACQSH standard, 'Partnering with consumers.' An alternative model is needed.

Noted in Media Watch, 18 November 2013, #332 (p.4):

- 'Palliative Care Services in Australia 2013,' Australian Institute of Health & Welfare, November 2013. <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129545131>

The end-of-life experience: Modifiable predictors of caregivers' bereavement adjustment

CANCER | Online – 2 December 2013 – Greater than 50% of the caregivers [i.e., study participants] reported regret about the cancer patient's end-of-life care; better patient quality of death reduced the risk of bereavement regret. The incidence of major depressive disorder or anxiety among the bereaved caregivers was 12.6% and was less likely for caregivers with better mental health before the loss of the patient. Better patient quality of death also predicted improved caregiver health-related quality of life. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.28495/abstract>

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International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2013/11/media-watch/>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/updates/international-palliative-care-resource-center-media-watch/>

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> [Scroll down to 'International Websites' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report]

Canada

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

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.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to 'Additional Resources']

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/news-events>

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://www.hospicehaz.hu/en/training/> [Scroll down to 'Media Watch']

U.K. | Omega, the National Association for End-of-Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

Care of the body after death

Nurses' perspectives of the meaning of post-death patient care

CLINICAL JOURNAL OF ONCOLOGY NURSING, 2013;17(2):647-651. Care of the body after death is an important nursing function that occurs in a wide variety of contexts. After a patient dies, nursing care continues as physical care of the body as well as care of the family members. In this descriptive, qualitative study, the authors explored nurse perceptions of what it means to care for the body after death. Two overarching themes emerged: 1) giving respectful and dignified after-death care (ADC) that is sensitive to the needs of the family; and, 2) ADC providing nurses with a mechanism for coping with care of dying patients. To ensure patient and family ADC needs are not superseded by nurses' own coping needs, comprehensive patient and family-centered ADC planning is recommended. <http://ons.metapress.com/content/r9527714j8048142/>

Of related interest:

- *END OF LIFE JOURNAL*, 2013;3(4). **'Postmortem/last offices nursing care effectiveness as perceived by U.S. licensed funeral directors.'** The findings [of this study] suggest post-mortem/last offices nursing care practices need to be considered carefully and be based on individual assessment. The participants' general consensus regarding physical aspects of post-mortem/last offices nursing care were largely in agreement with the nursing care practices that they typically observe. However, there were discrepancies that require further investigation. <http://endoflifejournal.stchristophers.org.uk/research/postmortem-last-offices-nursing-care-effectiveness-as-perceived-by-us-licensed-funeral-directors>

Noted in Media Watch, 14 June 2010, #153 (p.14):

- *NURSING TIMES* (U.K.) | Online OpEd – 11 June 2010 – **'Nurses need national guidance to standardise last offices care.'** Last offices mark the care transition between life and death. The processes integral to this make it explicit that patients are now dead; something that transforms an apparently simple procedure into a complex social and professional act, which is potentially emotionally difficult. <http://www.nursingtimes.net/nursing-practice-clinical-research/acute-care/nurses-need-national-guidance-to-standardise-last-offices-care-/5015832.article>

Noted in Media Watch 17 May 2010, #149 (p.9):

- *NURSING TIMES* (U.K.) | Online – 11 May 2010 – **'Last offices neglected in over half of hospital deaths.'** A dearth of training and guidance means nurses are failing to follow "last offices," the simple procedures for treating dead patients with dignity and respect. <http://www.nursingtimes.net/whats-new-in-nursing/acute-care/last-offices-neglected-in-over-half-of-hospital-deaths/5014365.article>

What should last offices involve?

If the patient is not catheterised, apply gentle pressure over the bladder to allow it to drain

Remove and record jewellery and any personal items, unless requested or advised otherwise

Attend to hygiene needs, particularly hair, nail and mouth care

Replace dentures

Attempt to close the eyes, using a small piece of clinical tape if required

Attach identification labels

Dress the patient in a gown/shroud or own clothes, as required

Place an incontinence pad under the buttocks to contain any soiling

Source: *Nursing Times*, May 2010.

Requests for non-disclosure of poor prognoses to patients

END OF LIFE JOURNAL, 2013;3(4). For patients who are given information about a life-limiting diagnosis and poor prognosis, it can be very distressing to hear words such as "terminal" and "end of life." These words are also upsetting for patients' family members/loved ones. In some instances, the family or surrogate decision-makers may ask that health professionals withhold the prognosis and distressing terminology by requesting non-disclosure of this health information to their loved one. These types of situations can be stressful to the healthcare professional and ethically problematic. Healthcare professionals may feel torn between doing what they perceive as being in the best interests of the patient and complying with the family's request for non-disclosure. This article explores the distress that being told about terminal prognoses causes patients and family members/loved ones and highlights some of the reasons for families requesting non-disclosure of terminal diagnosis. <http://endoflifejournal.stchristophers.org.uk/clinical-skills/requests-for-non-disclosure-of-poor-prognoses-to-patients>

Noted in Media Watch, 10 June 2013, #309 (p.9):

- *PSYCHO-ONCOLOGY* | Online – 18 March 2013 – '**If you had less than a year to live, would you want to know? A seven-country European population survey of public preferences for disclosure of poor prognosis.**' Among 9344 respondents [to this population based survey], data revealed an international preference (73.9%) to always be informed in the scenario of having a serious illness such as cancer with less than a year to live. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3283/abstract>

Palliative care and advanced dementia: The Croydon Project

END OF LIFE JOURNAL, 2013;3(4). The traditional model of specialist palliative care, with its high level of symptom support input in the last weeks/months of life, is not appropriate for people with dementia as the condition is associated with a longer, dwindling trajectory towards death, associated with progressive decline in physical and cognitive functioning. There is also a fear in some quarters that if people with dementia have access to specialist palliative care, services such as hospices will become inundated with referrals. Thus, there is an urgent need to develop models of palliative care services for people with advanced dementia and their carers. This article provides an overview of a 3-year project that was conducted by St. Christopher's Hospice ... with the aim of studying the problems faced by these patients and their families/carers and

developing a feasible model of specialist palliative care for advanced dementia. <http://endoflifejournal.stchristophers.org.uk/clinical-practice-development/palliative-care-and-advanced-dementia-the-croydon-project>

Dementia cases "set to treble worldwide" by 2050

U.K. | BBC News – 4 December 2013 – The number of people living with dementia worldwide is set to treble by 2050. Alzheimer's Disease International says 44 million people live with the disease, but that figure will increase to 135 million by 2050. In the U.K., dementia research receives one eighth of the amount of funding that is spent on cancer, which charities say is insufficient. <http://www.bbc.co.uk/news/health-25213162>

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>

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

Palliative Care Funding Review: Implications for family carers

END OF LIFE JOURNAL, 2013;3(4). In the U.K., widespread national variation in the funding and provision of end-of-life care services has led to an independent Palliative Care Funding Review being commissioned, the aim of which is to create a transparent funding system, with better outcomes for patients and value for the National Health Service.¹ The Review's proposed national per-patient funding model is currently being piloted. This article provides a critical analysis of the model, with a particular focus on its likely impact on family members caring for adults approaching the end of life. It outlines some of the challenges faced by family carers and discusses the importance of meeting their needs within the U.K.'s current social, economic and political context. It discusses how the Review's proposals are likely to meet or neglect particular needs of family carers. It is argued that, although the Review promotes holistic care and support for family carers, there do not appear to be clear funding mechanisms for the provision of such support. As a result, variations in the provision of supportive services for family carers are likely to continue, with potentially significant policy implications. <http://endoflifejournal.stchristophers.org.uk/professional-issues/palliative-care-funding-review-implications-for-family-carers>

1. *Funding the Right Care & Support for Everyone: Final Report of the Palliative Care Funding Review*, July 2011. [Noted in Media Watch, 4 July 2011, #208 (p.4)] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf

Population ageing and healthcare expenditure projections [in Scotland]: New evidence from a time to death approach

EUROPEAN JOURNAL OF HEALTH ECONOMICS | Online – Accessed 22 December 2013 – This article analyses, for the first time in Scotland, how expenditure projections for acute inpatient care are influenced when applying two different analytical approaches: 1) accounting for health-care (HC) spending at the end of life; and, 2) accounting for demographic changes only. The association between socioeconomic status and HC utilisation and costs at the end of life is also estimated. Time to death (TTD), age at death and the interaction between these two have a significant effect on HC costs. As individuals approach death, those living in more deprived areas are less likely to be hospitalised than those individuals living in the more affluent areas, although this does not translate into incurring statistically significant higher costs. Projected HCE for acute inpatient care for the year 2028 was approximately 7% higher under the demographic approach as compared to a TTD approach. Analysis showed that if death is postponed into older ages, HCE (and HC budgets) would not increase to the same extent if these factors were ignored. Such factors would be ignored if the population that is in their last year(s) of life were not taken into consideration when obtaining cost estimates. <http://link.springer.com/article/10.1007/s10198-013-0543-7#>

Effect of communication skills training for residents and nurse practitioners on quality of communication with patients with serious illness: A randomized trial

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2013;310(21):2271-2281. Communication about end-of-life care is a core clinical skill. Simulation-based training improves skill acquisition, but effects on patient-reported outcomes are unknown. Among internal medicine and nurse practitioner trainees, simulation-based communication training compared with usual education did not improve quality of communication about end-of-life care or quality of end-of-life care but was associated with a small increase in patients' depressive symptoms. These findings raise questions about skills transfer from simulation training to actual patient care and the adequacy of communication skills assessment. <http://jama.jamanetwork.com/article.aspx?articleid=1787407>

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Noted in Media Watch, 2 September 2013, #321 (p.10):

- *JOURNAL OF INTERPROFESSIONAL CARE* | Online – 21 August 2013 – '**Interprofessional, simulation-based training in end of life care communication: A pilot study.**' Results [of this study] indicated self-perceived improvements in knowledge, skills, confidence and competence when dealing with challenging end of life care communication situations. <http://informahealthcare.com/doi/abs/10.3109/13561820.2013.827163>

Of related interest:

- *AMA NEWS* | Online – 3 December 2013 – '**American Medical Association [AMA] guidelines call for prompt, thorough communication after unexpected death.**' Communication among next of kin, medical examiners, hospital staff members and other clinicians often is challenging. The information needs of these diverse interests vary, with the medical examiner seeking to determine the cause and manner of death in the interest of advancing criminal or civil justice and for public health purposes; the hospital and its medical professionals wanting to better understand the death of the patient for quality assurance purposes and to advance the science of medicine; and, the patient's next of kin desiring answers as to how and why their loved one died. AMA guidelines aim at improving communication during these situations.¹ <http://www.aafp.org/news-now/practice-professional-issues/20131203postmortemcomm.html>

1. 'American Medical Association guidelines for communication between hospitals, medical examiners, and next of kin following unexplained or unexpected deaths in the hospital.' <http://www.ama-assn.org/resources/doc/omss/postmortem-communication-guidelines.pdf>

The industry take-over of home birth and death

JOURNAL OF CLINICAL ETHICS, 2013;24(3):289-90. The generation in the U.S. who renewed interest in home birth is also returning to the tradition of funeral care at home. Caring for your own dead at home is legal in all 50 U.S. states. <http://www.clinicalethics.com/>

Oncologist factors that influence referrals to subspecialty palliative care clinics

JOURNAL OF ONCOLOGY PRACTICE | Online – 3 December 2013 – The authors [of this study] identified three main oncologist barriers to subspecialty palliative care referrals at sites with comprehensive palliative care clinics: 1) persistent conceptions of palliative care as an alternative philosophy of care incompatible with cancer therapy; 2) a predominant belief that providing palliative care is an integral part of the oncologist's role; and, 3) a lack of knowledge about locally available services. <http://jop.ascopubs.org/content/early/2013/12/02/JOP.2013.001130.abstract>

Learning and teaching palliative care: Can we do better?

JOURNAL OF PALLIATIVE CARE & MEDICINE | Online – Accessed 5 December 2013 – Palliative care and medicine are relative newcomers to the field of population health. With any new discipline comes an expectation that its practitioners are able to convey to those who don't know, what it is that is special or different about that discipline. Can we be sure that we are giving enough attention to learning and teaching of palliative care and medicine? Twenty years ago, James and MacLeod identified a number of aspects of palliative care education that were problematic.¹ There are a number of those elements that remain potentially problematic today, particularly with regard to the way in which they are addressed in teaching. They include the lack of a long tradition and adequate conceptualisation of palliative care; the significance of psychological, emotional and spiritual aspects of care; the importance of, but at times, inadequate understanding of symptom management; the multi- and inter-professional nature of palliative care; the range of different settings of palliative care and the fact that palliative caregivers work in situations where the emotional, psychological and spiritual demands on them may be immense. Over the last two decades there have been huge advances in all aspects of palliative care but there remain challenges for the way in which it is taught. <http://www.omicsgroup.org/journals/Learning-and-Teaching-Palliative-Care-Can-We-Do-Better-2165-7386.1000e124.pdf>

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1. 'The problematic nature of education in palliative care,' *Journal of Palliative Care*, 1993;9(4):5-10. There are many aspects of palliative care that are problematic, particularly in palliative care education: a) lack of a long tradition and adequate conceptualization of palliative care; b) significance of psychological, emotional, and spiritual aspects; c) importance of but inadequate understanding of symptom control; d) fact that palliative care is not curative in the accepted sense; e) its multi-professional nature; f) range of different settings of palliative care; and, g) palliative caregivers have to perform their duties in situations where the emotional and psychological demands on them may be immense. General issues relevant to palliative care education are reviewed. <http://www.ncbi.nlm.nih.gov/pubmed/7510805>

Noted in Media Watch, 26 November 2012, #281 (p.12):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2012;2(4):292-293. '**Can e-learning be used to teach end-of-life care?**' Many clinicians and educators regard e-learning with scepticism, especially in relation to a subject as personal and sensitive as end-of-life care. This is especially the case if they have been exposed to poorly designed e-learning programmes, or those that appear irrelevant, simplistic or not rooted in the real world of practice. The increasing pressure to complete requirements for statutory and mandatory training through e-learning programmes has increased the aversion that some clinicians have toward this whole way of learning. <http://spcare.bmj.com/content/2/4/292.extract>

Noted in Media Watch, 19 November 2012, #280 (p.10):

- *ILLNESS, CRISES & LOSS*, 2012;20(4):375-386. '**Interdisciplinary education in palliative care: A bold strategy, solution and political statement.**' Experience reveals preparing the interdisciplinary palliative care team members cannot be accomplished by sequestering students in single-discipline training. By combining different ways of knowing and being, the underlying tenets of interdisciplinary education, we must – by design, curriculum, teaching strategies and research – reflect the nature and practice of the interdisciplinary palliative care team. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue.5.12;journal.1.72;linkingpublicationresults.1:103734.1>

Centers for Medicare & Medicaid Services issues new surveyor guidance on Initiating CPR in nursing homes and facility cardiopulmonary resuscitation/do not resuscitate policies

THE NATIONAL LAW REVIEW (U.S.) | Online – 30 November 2013 – In a highly publicized recent case in California, a registered nurse working in an independent living facility refused to initiate cardiopulmonary resuscitation (CPR) on an elderly resident who was experiencing respiratory distress. The nurse refused to start CPR even when the 911 dispatcher begged her to start CPR or to find someone, even a bystander, who would do so. The nurse still refused, stating that the facility had a no-CPR policy at the time. This case caused consternation among long term care providers around the country. In our own practice, we've had numerous requests to review skilled nursing facility (SNF) Do Not Resuscitate (DNR) and CPR policies because of this case. On 1 October 2013, the Centers for Medicare & Medicaid Services (CMS) issued new surveyor and provider guidance on CPR/DNR policies and practices in SNFs that leaves no doubt about: 1) an SNF's obligations to provide CPR consistent with residents' advance directives; and, 2) the requirement that SNFs have policies and procedures consistent with this requirement.¹ <http://www.natlawreview.com/article/centers-medicare-medicare-services-cms-issues-new-surveyor-guidance-initiating-cpr-n>

Noted in Media Watch, 11 March 2013, #296 (p.2):

- CALIFORNIA | *The Los Angeles Times* – 5 March 2013 – '**Dead woman's family won't sue seniors' facility.**' The 87-year-old woman, who died after a staff member at a senior living facility refused to perform CPR, did not want life-prolonging intervention, her family said. A staff member, who identified herself as a nurse, refused to give the woman CPR as directed by a Bakersfield fire dispatcher, saying it was against policy for staff to do so, according to a 911 tape released by the Bakersfield Fire Department.¹ <http://www.latimes.com/news/local/la-me-0306-bakersfield-cpr-20130306.0,5584341.story?track=rss>

Cont.

Of related interest:

- *AGING CLINICAL & EXPERIMENTAL RESEARCH* | Online – November 2013 – **'Mandating advance directives [in the U.S.]'** As the population ages, end-of-life care (EOLC) costs become an increasingly pressing subject. Although Ads [advance directives] have been shown to reduce EOLC costs, most people do not have ADs. To address this issue, the authors propose that Congress instruct the Centers for Medicare & Medicaid Services to collect ADs from Medicare beneficiaries. Because ADs can improve care and reduce unnecessary spending, this solution would likely be attractive to a broad coalition of support from providers, insurers, and the public. <http://link.springer.com/article/10.1007/s40520-013-0167-x>

Place of death and end-of-life transitions experienced by very old people with differing cognitive status: Retrospective analysis of a prospective population-based cohort aged 85 and over

PALLIATIVE MEDICINE | Online – 6 December 2013 – Most very old community-dwelling individuals [i.e., study participants], especially the severely cognitively impaired, died away from home. Findings also suggest that long-term care may play a role in avoidance of end-of-life hospital admissions. These results provide important information for planning end-of-life services for older people across the cognitive spectrum, with implications for policies aimed at supporting home deaths. <http://pmj.sagepub.com/content/early/2013/12/05/0269216313510341.abstract>

A prospective evaluation of Dignity Therapy in advanced cancer patients admitted to palliative care

PALLIATIVE MEDICINE | Online – 5 December 2013 – Dignity Therapy is a brief, psychosocial intervention for patients with incurable disease. Over 2 years, 80 of 341 eligible patients [i.e., study participants] completed Dignity Therapy. 55 patients completed evaluations, of whom 73-89% found Dignity Therapy helpful, satisfactory and of help to relatives; 47-56% reported that it heightened their sense of purpose, dignity and will to live. Patients with children and lower performance status, emotional functioning and quality of life were more likely to report benefit. This study adds to the growing body of evidence supporting Dignity Therapy as a valuable intervention in palliative care; a substantial subset of patients facing end of life found it manageable, relevant and beneficial. <http://pmj.sagepub.com/content/early/2013/12/03/0269216313514883.abstract>

Noted in Media Watch, 25 November 2013, #333 (p.11):

- *FOCUS*, 2013;11(4):576-587. **'Effect of Dignity Therapy on distress and end-of-life experience in terminally ill patients: A randomised controlled trial.'** Dignity therapy [in this study] was significantly better than client-centred care in improving spiritual wellbeing, and was significantly better than standard palliative care in terms of lessening sadness or depression. <http://focus.psychiatryonline.org/article.aspx?articleID=1769661>

"End of Life Diabetes Care: A Strategy Document": Where are we one year on in the light of the review of The Liverpool Care Pathway?

PRACTICAL DIABETES, 2013;30(90):355-356. Abstract or a link to the article is unavailable without purchase subscription. <http://onlinelibrary.wiley.com/doi/10.1002/pdi.1810/abstract>

N.B. End of Life Diabetes Care: A Strategy Document Commissioned by Diabetes U.K., July 2012. <http://www.leicestershirediabetes.org.uk/uploads/123/documents/End%20of%20Life%20Diabetes%20Care%20Stategy%20Document%20Final%20170712.pdf>

Physicians' experiences and perspectives regarding the use of continuous sedation until death for cancer patients in the context of psychological and existential suffering at the end of life

PSYCHO-ONCOLOGY | Online – 5 December 2013 – In the studied countries [Belgium, The Netherlands, and the U.K.], three groups of patients were distinguished regarding the origin of their psychological and existential suffering. The first group had pre-existing psychological problems before they became ill, the second developed psychological and existential suffering during their disease trajectory, and the third presented psychological symptoms that were characteristic of their disease. Before they resorted to the use of sedation, physicians reported that they had considered an array of pharmacological and psychological interventions that were ineffective or inappropriate to relieve this suffering. Necessary conditions for using sedation in this context were for most physicians the presence of refractory symptoms, a short life expectancy, and an explicit patient request for sedation. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3450/abstract>

Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review

SCANDINAVIAN JOURNAL OF PRIMARY HEALTH CARE, 2013;31(4):215-226. All barriers and facilitators identified were categorized as GP characteristics, perceived patient factors, or health care system characteristics. Stronger evidence was found for the following: 1) lack of skills to deal with patients' vague requests; 2) difficulties with defining the right moment; 3) the attitude that it is the patient who should initiate ACP [advance care planning]; and, 4) fear of depriving patients of hope. Stronger evidence was found for the following facilitators: 1) accumulated skills; 2) the ability to foresee health problems in the future; 3) skills to respond to a patient's initiation of ACP; 4) personal convictions about who to involve in ACP; and, 5) a longstanding patient – GP relationship and the home setting. <http://informahealthcare.com/doi/abs/10.3109/02813432.2013.854590>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *END OF LIFE JOURNAL*, 2013;3(4). 'The judgment of the High Court [of England] in two right-to-die cases.' This article summarises the judgment from the High Court cases of Tony Nicklinson and 'Martin.' Both suffered from locked-in syndrome secondary to catastrophic physical disabilities, but their mental processes were unimpaired. 'Martin' wanted the then Director of Public Prosecutions to clarify his policy on assisted dying so people, including family members, doctors and solicitors, who were willing to assist 'Martin' to commit suicide via the Dignitas clinic in Switzerland, would know definitively whether they would face prosecution in England. Nicklinson sought a court declaration that it should not be unlawful, on the grounds of necessity, for any doctor to terminate, or assist to terminate, his life, and that the current law of murder and/or assisted suicide was incompatible with Article 8 of the Human Rights Act 1998. The High Court rejected applications for judicial review. It is not the intention of this article to debate issues relating to assisted suicide, physician-assisted suicide and voluntary euthanasia but provide readers with insight into the legal deliberations relating to this High Court judgment. <http://endoflifejournal.stchristophers.org.uk/legal-discussions/the-judgment-of-the-high-court-in-two-right-to-die-cases>

Noted in Media Watch, 20 August 2012, #267 (p.4)

- U.K. (ENGLAND & WALES) | BBC News – 16 August 2012 – 'Tony Nicklinson loses High Court right-to-die case.' A man paralysed from the neck down has lost his High Court case to allow doctors to end his life without fear of prosecution. Tony Nicklinson, 58 ... communicates by blinking and has described his life as a "living nightmare" since a stroke in 2005. Mr. Nicklinson said he would appeal against the decision. The case went further than previous challenges to the law in England & Wales on assisted suicide and murder. Another man, known only as Martin, who is 47, also lost his case to end his life with medical help. <http://www.bbc.co.uk/news/health-19249680>

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- *JOURNAL OF MEDICAL ETHICS* | Online – 5 December 2013 – '**Non-physician-assisted suicide in The Netherlands: A cross-sectional survey among the general public.**' In The Netherlands, approximately 45% of patients' requests for euthanasia are granted by a physician. After a rejected request, some patients approach non-physicians and ask them for assistance in suicide. The aim of this study was to investigate the opinion of the Dutch general public on non-physician-assisted suicide. The Dutch general public [i.e., survey participants] consider non-physician-assisted suicide in some specific cases a tolerable alternative for patients with a rejected request for physician-assisted dying if the assistance is limited to the provision of information. However, the majority do not support the legalisation of non-physician-assisted suicide. <http://jme.bmj.com/content/early/2013/12/05/medethics-2013-101736.abstract>
- *JOURNAL OF MEDICAL LAW & ETHICS*, 2013;1(2):141-149. '**Should physicians who assist suicide be severely punished? A pilot study conducted in France.**' In France, physician-assisted suicide is illegal. It is not known, however, to what extent and under what circumstances French lay people and health professionals think that physicians who provide patients with the means to end their lives should be punished. Ninety-four participants ... judged the extent to which a physician must be punished in each of 36 possible cases. These cases (scenarios) were composed of all combinations of four factors: patient's age, level of incurability, type of suffering, and whether the patient requested a life-ending procedure. Four qualitatively distinct positions were found: severe penalty in all cases (18%); penalty must depend on circumstances (32%); not severe penalty (38%); and, no penalty at all (12%). <http://www.ingentaconnect.com/content/plp/jmle/2013/00000001/00000002/art00004>
- *MEDICAL LAW INTERNATIONAL* | Online – 3 December 2013 – '**Reporting and scrutiny of reported cases in four jurisdictions where assisted dying is lawful: A review of the evidence in The Netherlands, Belgium, Oregon and Switzerland.**' The authors assess the available empirical evidence on reporting and what it tells us about the effectiveness of such requirements in encouraging reporting. They also look at the nature of requirements on regulatory bodies to refer cases not meeting the legal criteria to either prosecutorial or disciplinary authorities. The authors assess the evidence available on the outcomes of reported cases, including the rate of referral and the ultimate disposition of referred cases. <http://mli.sagepub.com/content/early/2013/11/29/0968533213508973.abstract>

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Worth Repeating

Ethical issues in end-of-life geriatric care: The approach of three monotheistic religions – Judaism, Catholicism, and Islam

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY, 2003;51(8):1149-1154. Ethical dilemmas pervade modern geriatric medicine. What is considered right or wrong will differ depending on, among other things, the patient's religion. The three Abrahamic monotheistic religions, Judaism, Christianity (its Catholic variant), and Islam all have carefully considered positions on medical ethics. Although much is held in common, there are significant differences. The authors present three clinical cases, each of which presents ethical dilemmas typical of geriatric care, especially at the end of life. On the basis of these scenarios, the normative ethical position of each religion is compared and contrasted. It is hoped that this approach will offer the geriatrician a useful approach to treating patients in an increasingly multicultural society. <http://onlinelibrary.wiley.com/doi/10.1046/j.1532-5415.2003.51364.x/pdf>

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