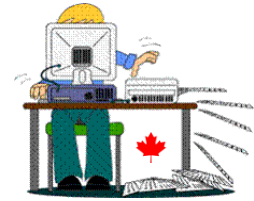


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Philosophy and practice of end-of-life care: Scroll down to [Specialist Publications](#) and 'Teleological care and the last years of life' (p.9), in *Journal of Evaluation in Clinical Practice*.

[Canada](#)

New palliative care council aims to improve local care

ONTARIO | *The Hamilton Spectator* – 16 July 2014 – A new palliative care council will help improve end-of-life services for Hamilton patients and their families, local health officials say. The province's palliative care system is fragmented and reactive, rather than proactive, says Dr. Denise Marshall, chair of Ontario's Collaborative Palliative Care Clinical Council. "Patients often do not receive the support and treatment they need to end life as comfortably as possible because their health-care providers and families aren't properly educated about palliative care," Marshall said. "What needs to be considered sooner is whether the patient is likely to die within a year. If the answer is yes, the appropriate end-of-life care needs to be planned." These are some of the issues the Regional Hospice Palliative Care Program Council ... hopes to address. The council draws on the expertise of healthcare professionals who will make recommendations about how to improve end-of-life care to the Hamilton Niagara Haldimand Brant Local Health Integration Network. <http://www.thespec.com/news-story/4635353-new-palliative-care-council-aims-to-improve-local-care/>

Noted in Media Watch, 30 June 2014, #364 (p.1):

- ONTARIO | *The Hamilton Spectator* – 26 June 2014 – '**Local palliative care for cancer patients found lacking.**' The number of cancer patients in Hamilton and area who didn't get a palliative assessment within a year before their death was much larger than the Ontario average, according to a report rating the quality of cancer care.¹ A key recommendation in the Cancer System Quality Index report urges that all patients at the end of life "be referred to palliative care services earlier," and says they "may not have adequate access to the resources and supports they need to live and die in the setting of their choice." It also found that earlier access to palliative care would reduce hospital use near the end of life. The rating showed the Hamilton Niagara Haldimand Brant Local Health Integration Network had a higher rating than the Ontario average when it comes to keeping cancer patients out of the emergency department and from being admitted to hospital. <http://www.thespec.com/news-story/4599129-local-palliative-care-for-cancer-patients-found-lacking/>

1. 'Cancer System Quality Index 2014,' Cancer Quality Council of Ontario, June 2014. <http://www.csqi.on.ca/>

U.S.A.

The CPR we don't see on TV

THE NEW YORK TIMES | Online – 17 July 2014 – Precise survival rates after receiving CPR are tough to come by and vary according to patients' underlying health status. Research generally suggests about 40% of patients who receive CPR after experiencing cardiac arrest in a hospital survive immediately after being resuscitated,¹ and only 10 to 20% survive long enough to be discharged. Research also suggests patients significantly overestimate the likelihood of success. A recent [*sic*] study of older patients found 81% believe their chances of leaving the hospital after CPR are greater than 50%, and almost a quarter believe their chances are higher than 90%. This discrepancy is important because patients' preferences for CPR are strongly related to their perception of how likely it is to be successful: Older adult patients are half as likely to want CPR near the end of life when they are told the true probability of survival. Some

have suggested misrepresentations of CPR on television may lead patients to have unrealistic expectations of what the procedure entails and the likelihood of success.³ http://well.blogs.nytimes.com/2014/07/17/the-cpr-we-dont-see-on-tv/?_php=true&_type=blogs&ref=health&_r=0

Specialist Publications

'Timing of palliative care consultations and recommendations: Understanding the variability' (p.7), in *American Journal of Hospice & Palliative Medicine*.

'The presence of hospital-based palliative care programs: A resource dependence perspective' (p.9), in *Healthcare Management Review*.

1. 'Resuscitation on television: Realistic or ridiculous? A quantitative observational analysis of the portrayal of cardiopulmonary resuscitation in television medical drama,' *Resuscitation*, 2009; 80(11):1275-1279. Whilst the immediate success rate of CPR in medical television drama does not significantly differ from reality, the lack of depiction of poorer medium to long term outcomes may give a falsely high expectation to the lay public. Equally the lay public may perceive that the incidence and likely success of CPR is equal across all age groups. [http://www.resuscitationjournal.com/article/S0300-9572\(09\)00403-1/abstract](http://www.resuscitationjournal.com/article/S0300-9572(09)00403-1/abstract)
2. 'How misconceptions among elderly patients regarding survival outcomes of inpatient cardiopulmonary resuscitation affect do-not-resuscitate orders,' *Journal of the American Osteopathic Association*, 2006;106(7):402-404. A significant number participants [in this oral standardized study] had standing DNR orders despite demonstrating extremely optimistic beliefs about CPR. <http://www.jaoa.org/content/106/7/402.abstract>
3. 'The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation,' *The New England Journal of Medicine*, 1994;330(8):545-549. Most older patients do not want CPR once they understand the probability of survival after the procedure. <http://www.nejm.org/doi/full/10.1056/NEJM199402243300807#t=articleResults>

Coordinated care for those nearing life's end – but does it save money?

CALIFORNIA | Jefferson Public Radio (Redding) – 16 July 2014 – After contentious debate over death panels four years ago, federal lawmakers are again taking up issues around end-of-life care. They're investing money into programs that care for the nation's sickest patients in a new way. One of them is based at Sutter Health in Northern California – and it could be a model for the rest of the country. [The Advanced Illness Management program, or AIM. is] not hospice. This program is for the pre-hospice population, people estimated to be in the last 18 months of life. The AIM program assigns a team of doctors, nurses and social workers to help patients transition home after hospital stays, manage medication, and carefully coordinate care, at home and over the phone, to help keep patients out of the hospital. <http://ijpr.org/post/coordinated-care-those-nearing-life-s-end-does-it-save-money>

End-of-life care advocate never talked with her own dad about his wishes

WASHINGTON DC | *National Journal* (OpEd) – 16 July 2014 – The day my father died from prostate cancer ... is the day I decided that no family should ever experience the same pain. That day everything changed for me. I had worked for seven years at an organization whose sole focus is end-of-life care, yet I had not had even one conversation with my father about his end-of-life wishes. It was truly a wake-up call, an eye-opening experience I hope I never have to repeat. Imagine sitting in a hospital room with your unresponsive father, your five siblings on one side of the bed, and his new wife and her five children on the other side. It was like a stare-down session before a big competitive match. People on both sides thought they were best equipped to speak on my father's behalf. The sad reality is that none of us – not one of the 11 people in that room – had a clue about what he wanted. He had no advance directive, had never had a serious conversation about his end-of-life wishes, not even with me, an end-of-life care advocate. Since that day three-and-a-half years ago, I have learned that horrible situations at the end of life are far too common in this country, especially among people of color – and the African-American community in particular. African Americans are "dying from treatable and preventable illnesses with more frequency than other ethnic groups. The research indicates that racial and ethnic minorities are less likely to receive even routine medical procedures and experience a lower quality of health services," even when insured.¹ This disparity means patients are more likely to distrust terminal and otherwise grim diagnoses, endure unwanted medical treatments, and experience unnecessary pain and family strife. <http://www.nationaljournal.com/next-america/perspectives/end-of-life-care-advocate-never-talked-with-her-own-dad-about-his-wishes-20140716>

1. 'Unequal Treatment: Confronting Racial & Ethnic Disparities in Health Care,' Institute of Medicine, National Academy of Sciences, March 2002. <http://www.iom.edu/Reports/2002/Unequal-Treatment-Confronting-Racial-and-Ethnic-Disparities-in-Health-Care.aspx>

Of related interest:

- WASHINGTON DC | *Health News Digest* – 15 July 2014 – **'10 questions to ask aging parents about end-of-life care.'** If you have aging parents, now is the time to discuss what's important to them as they near the end of their lives. Too many adult children wait to have end-of-life conversations when their parents are dying or in the midst of a crisis. <http://www.healthnewsdigest.com/news/aging%20issues0/10-Questions-To-Ask-Aging-Parents-About-End-of-Life-Care.shtml>

Elder law: Nursing home care may be unavoidable

TEXAS | *The Houston Chronicle* – 15 July 2014 – Caring for a person with dementia takes a tremendous mental and physical toll on the caregiver. Various symptoms include memory loss, mood swings, agitation and aggression, personality changes, hallucinations, and frequent falling. Constant supervision is required to prevent disastrous consequences of the symptoms. Numerous other illnesses in older adults require just as much care and supervision as those with dementia. An exhausted caregiver may not realize how tired he or she is, possibly leading to an injurious accident. When the level of care a person needs surpasses what may be provided at home, it's time to consider a long-term care environment. Communication between family members about this issue is important, though it's not always possible. It

is not always necessary for the primary caregiver to obtain the consent of other family members before admitting a loved one to a nursing facility. When challenging family dynamics exist, seeking advice from an experienced elder law attorney may help. http://www.chron.com/homes/senior_living/article/Elder-Law-Nursing-home-care-may-be-unavoidable-5622945.php

Specialist Publications

'Awareness of dementia by family carers of nursing home residents dying with dementia: A post-death study' (p.12), in *Palliative Medicine*.

International

Elder care in the U.K.

Jeremy Hunt unveils new measures to tackle failing care homes

U.K. | *The Guardian* – 16 July 2014 – There are far too many failing care homes that people would not be happy to send their relatives to, the health secretary has said. Jeremy Hunt said he would not want his mother, father or grandparents to live in a number of facilities in England as he announced new measures to tackle failing care homes. The country's chief inspector of social care said that examples of "truly awful care" were brought to light every week. Andrea Sutcliffe condemned the abuse and neglect that still occurred and pledged to crack down on the unacceptable care provided by some organisations. Her comments came as Hunt announced that poorly performing care homes would be put into a similar failure regime as inadequate hospitals. Hunt said that most of the hospital trusts put into special measures a year ago had shown significant improvements, and that the initiative would be rolled out to include care homes and home care services. If these services fail to make improvements they could then face being shut down, he said. <http://www.theguardian.com/society/2014/jul/16/jeremy-hunt-new-measures-tackle-failing-care-homes>

End-of-life care in Australia

Wagga MP's palliative care brochure described as more "promotion" than "information"

AUSTRALIA (New South Wales) | ABC News (Wagga, Wagga) – 15 July 2014 – A brochure produced by Liberal Member for Wagga, Daryl Maguire, on palliative care for the region has been described as creating more questions than answers. The 18-page booklet was recently delivered to mailboxes around the electorate and discusses the state government's palliative care plan, Wagga's Palliative Care Alliance, and developments at the Calvary Hospital and Forrest Centre. The Labor candidate for Wagga, Daniel Hayes, has praised Mr. Maguire for taking an interest in the issue but has described the brochure as more "promotion" rather than "information." Mr. Hayes, who is a psychologist, says it is lacking in certain details. Questions have also been raised over how the Wagga Palliative Care Alliance will operate beyond next year, when Medicare Locals are disbanded. <http://www.abc.net.au/news/2014-07-15/palliative-brochure/5596800>

Ireland's Committee on Health & Children report

Automatic medical cards for end-of-life care recommended

IRELAND | Raidió Teilifís Éireann (Dublin) – 15 July 2014 – A Joint Oireachtas Committee on Health & Children report has said the automatic issue of medical cards should be considered for people requiring end-of-life care.¹ The report on end-of-life care made thirty-seven recommendations. It called for a national strategy on palliative care and said each hospital should have a designated person to ensure compliance with good standards. On the medical card issue, it said an alternative would be to extend the renewal period for discretionary medical cards for those requiring end-of-life care to twelve months. The report suggested that a specialist palliative care budget be established, ring-fencing funding for a minimum of five years. It said the Government should look at tackling the regional disparities in funding of specialist palliative care services. Committee chairman Jerry Buttimer said evidence presented to the joint committee at its hearings suggested inequalities based solely on geographic location. The report also said quality standards should be developed for the funeral services industry, along with an oversight mechanism. <http://www.rte.ie/news/2014/07/15/630909-medical-cards-health/>

1. 'Report on End of Life and Palliative Care in Ireland,' Joint Oireachtas Committee on Health & Children, 2014. http://www.oireachtas.ie/parliament/oireachtasbusiness/committees_list/health-and-children/reports/

End-of-life care in Serbia

This is not a ward for dying people: Palliative care unit in Cacak

SERBIA | inSerbia – 15 July 2014 – In the palliative care unit at the General Hospital in Cacak, Dr. Danka Dragicevic and her colleagues have dedicated themselves to the patients and their families 24 hours a day. There are no specified visiting hours in the unit, visitors can come at any time and stay as long as they wish. Doors depicting open arms and butterflies are always open to family members to visit their loved ones who receive around the clock care. While in Serbia palliative care has been developing for over a decade, the major progress in this field was achieved in the last three years with the financial support of the European Union through the project 'Development of Palliative Care in Serbia,' financially and strategically supported by the Ministry of Health.¹ <http://inserbia.info/today/2014/07/this-is-not-a-ward-for-dying-people-palliative-care-unit-in-cacak/>

1. 'Developing Palliative Care Services in Serbia' <http://www.opml.co.uk/projects/developing-palliative-care-services-serbia>

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

Campaigners reject new end of life care guidance

U.K. (England) | *Independent Catholic News* – 14 July 2014 – In a statement released to mark the first anniversary of the recommended abolition of The Liverpool Care Pathway [LCP] by the Neuberger Report of 15 July 2013,¹ Alert & Distant Voices express their concerns that ... new guidance produced by the Leadership Alliance for the Care of Dying People,² retains the central flaws of the discredited end-of-life protocol and therefore represents a cynical exercise in rebranding. They contend the 'New Priorities for Care,' which will replace the LCP, will offer nothing new to protect those who are not dying from being unlawfully killed in the same way as the many whose lives were ended under the pathway. The Neuberger Report recognized that a central flaw of the LCP was its unscientific claim that medical professionals could definitively diagnose dying, which led many families to suspect that their loved ones were put on the pathway when they might have otherwise survived. Baroness Neuberger recommended research into the biology of dying and the use of evidence-based prognostic tools (including awareness of their limitations) which might help to predict death. <http://www.indcatholicnews.com/news.php?viewStory=25155>

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>
2. 'One chance to get it right: Improving people's experience of care in the last few days and hours of life,' Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.7)] <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

Cont. next page



Barry R. Ashpole

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

Of related interest:

- U.K. (England) | *The Guardian* – 15 July 2014 – **'Hospitals continue to fail patients at end of life.'** While the new 'Priorities for Care' are laudable ... little if anything will change unless those at the frontline of care delivery are equipped to put them into practice. And this requires an investment in education and training. High quality care does not come cheap and if National Health Service England and the Department of Health wish to avoid further embarrassing reports on the management of vulnerable and dying people in our acute hospitals, politicians must accept the responsibility to open the discussion about how money is spent on healthcare rather than how money can be saved. <http://www.theguardian.com/healthcare-network/2014/jul/15/hospitals-failing-dying-end-of-life-patients>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Economist* – 19 July 2014 – **'Assisted suicide: Easeful death.'** The arguments against assisted suicide are strongly held. Many people object on moral or religious grounds, while some doctors say that it conflicts with their oath to "do no harm." Opponents add that vulnerable people may feel pressure to spare their carers the burden – or, worse, may be bullied into choosing suicide. And there is a broader argument that allowing assisted suicide in some cases will create a slippery slope, with ever more people being allowed (or forced) to take their own lives, even for trivial reasons. But the arguments in favour are more compelling. In a pluralistic society, the views of one religion should not be imposed on everybody. Those with a genuine moral objection to assisted suicide need not participate. What a doctor sees as harm a patient may see as relief; and anyway it is no longer standard for medical students to take the Hippocratic Oath. The hardest argument concerns vulnerable people: they may indeed feel pressure, but that is simply a reason to set up a robust system of counselling and psychiatric assessment, requiring the agreement of several doctors that a patient is in their right mind and proceeding voluntarily. <http://www.bbc.co.uk/programmes/b00w7gtn>

Of related interest:

- U.K. | BBC News – 18 July 2014 – **'Assisted dying: Viewpoints from Lords debate.'** The House of Lords is debating plans to legalise assisted dying. More than 130 peers have asked to take part. Here is a flavour of what they have been saying. <http://www.bbc.com/news/uk-politics-28365404>
- U.K. | BBC News – 17 July 2014 – 'Euthanasia and assisted suicide laws around the world.' <http://www.theguardian.com/society/2014/jul/17/euthanasia-assisted-suicide-laws-world>
- U.K. | *The Times* – 16 July 2014 – **'Most believers back assisted dying despite opposition of church leaders.'** Church leaders are out of touch with their congregations on the issue of assisted dying, according to research that found about 70% of believers want to see a change in the law. A majority of Anglicans, Jews and Roman Catholics all want assisted dying for terminally ill people to be legalised, with only Baptists, Muslims and Hindus against a change. <http://www.thetimes.co.uk/tto/faith/article4148558.ece>
- INDIA | *The Times of India* (New Delhi) – 16 July 2014 – **'Supreme Court wants countrywide debate on legalizing euthanasia.'** The Supreme Court issued notice to all states and union territories on a plea for legalizing passive euthanasia. An apex court constitution bench ... issued the notice on a plea filed with it saying the question of passive euthanasia needs a comprehensive examination as there was no authoritative judicial pronouncement on the issue. <http://timesofindia.indiatimes.com/india/SC-wants-countrywide-debate-on-legalizing-euthanasia/articleshow/38475491.cms>

[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.14.

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

Distance no impediment for funerals: Death as a uniting ritual for African people – A pastoral study

ACADEMIC JOURNAL OF THE CENTRE FOR MINISTERIAL DEVELOPMENT (South Africa) | Online – 9 July 2014 – An African funeral is a very social event for the entire community in which the deceased lived. Regardless of whether the deceased was a Christian or not, death has always been a reunion for long-separated relatives, believers and non-believers. Nowadays, tents, cars and the gathering of multitudes of people demonstrate how death can bring people together, irrespective of distance and relationships. Of course, this is not to deny the fact that death can be a cause of division between relatives and friends. Nonetheless, the funeral itself is also a uniting factor; many people come together, regardless of distance, to pay their last tributes to the deceased and to provide the bereaved family with emotional support. In this article, the author argues that death, amongst other things, is a uniting factor that is able to bring people, who are separated by distance and other factors, together. The aim of this article is to discuss how death invites people into a family, regardless of bad blood, flawed relationships and separation. <http://ve.org.za/index.php/VE/article/view/1248/2126>

Noted in Media Watch, 1 October 2012, #273 (p.4):

- ZAMBIA | *Daily Mail* (Lusaka) – 24 September 2012 – '**Traditional African funerals: A once-beautiful thing.**' When death knocks on a family's door, the African social fabric comes alive. At its core, a traditional African funeral is a beautiful thing. It is supportive, communal, collective, healing, and a shared process of delegated efficiency amongst family, relatives and friends in a place of common purpose. <http://www.daily-mail.co.zm/?p=15189>

Psychosocial care and the role of clinical psychologists in palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 July 2014 – The following themes were identified [in this study]: 1) the essential nature of the psychologists' care were caring and company; 2) the dynamic process included psychological assessment, intervention, and evaluation based on psychological knowledge; 3) they needed to modify their care using an integrative framework, by setting practical goals and using techniques with flexibility; and, 4) they faced external and internal challenges in this field. Clinical psychologists have beneficial contributions but have to modify psychosocial care based on the patients' needs and clinical situations. <http://ajh.sagepub.com/content/early/2014/07/11/1049909114543492.abstract>

Noted in Media Watch, 19 May 2014, #358 (p.4):

- *AMERICAN PSYCHOLOGIST*, 2014;69(4):364-376. '**Opportunities for psychologists in palliative care: Working with patients and families across the disease continuum.**' Relatively few [interdisciplinary palliative care] teams formally include psychologists, although their skills of enhancing patients' and families' well-being and lessening suffering make an enormous contribution to the care provided. <http://www.apa.org/pubs/journals/releases/amp-a0036735.pdf>

Timing of palliative care consultations and recommendations: Understanding the variability

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 July 2014 – The effectiveness of palliative care consultation teams depends ... on their timely utilization by other providers. The goal of this study was to examine the timing of palliative care consultation requests and responses at a single Veteran Affairs Medical Center. The median interval between admission and consultation request was 5 days... The median interval between consultation request and death was 23 days... There is substantial variability in when patients receive a palliative care consultation. Many receive palliative care within the first week of hospitalization and their final month of life. <http://ajh.sagepub.com/content/early/2014/07/11/1049909114543322.abstract>

The role of palliative rehabilitation in the preservation of personhood at the end of life

BMJ CASE REPORTS | Online – 9 July 2014 – Progressive advancements in the fields of medicine, oncology and palliative care have seen significant gains in the life expectancy but have also resulted in patients living longer with the burdens of cancer. It is within the sphere of end-of-life care that the role of palliative rehabilitation comes into its own in addressing the effects of increased physical and psychological morbidity that accompany many of these prognostic gains. Focusing on the cancer journey, the authors highlight the impact of rehabilitative measures on efforts to preserve the personhood of a patient with metastatic renal cell carcinoma and thus maintain her dignity and quality of life and provide her with appropriate and effective holistic care at the end of life. <http://casereports.bmj.com/content/2014/bcr-2014-204780.full>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – Accessed 15 July 2014 – **"My body's falling apart" Understanding the experiences of patients with advanced multi-morbidity to improve care: Serial interviews with patients and carers.** The authors report the experiences and perceptions of people with advanced multi-morbidity to inform improvements in palliative and end-of-life care. Patients with advanced multi-morbidity received less care than their illness burden would appear to merit. Some people did restrict their interactions with care providers to preserve autonomy, but many had a limited understanding of their multiple conditions, medications and available services, and found accessing support impersonal and challenging. <http://spcare.bmj.com/content/early/2014/05/28/bmjspcare-2013-000639>

Pathologizing suffering and the pursuit of a peaceful death

CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS | Online – 17 July 2014 – Psychiatry has a long-standing, virtually monolithic view a desire to die, even a desire for a hastened death among the terminally ill, is a manifestation of mental illness. Psychiatry has made inroads into hospice and palliative care, and in doing so brings with it the conviction dying patients who seek to end their suffering by asserting control over the time and manner of their inevitable death should be provided with psychotherapeutic measures rather than having their expressed wishes respected as though their desire for an earlier death were the rational choice of someone with decisional capacity. This article reviews ... this approach from the perspective of recent data indicating patients who secure and utilize a lethal prescription are generally exercising an autonomous choice unencumbered by clinical depression or other forms of incapacitating mental illness. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9304360&fulltextType=RA&fileId=S0963180114000085>

Of related interest:

- *RIVISTA DI PSICHIATRIA*, 2014;49(3):106-114. **'Bereavement and complicated grief: Towards a definition of Prolonged Grief Disorder for DSM-5.'** Prolonged distress and disability in connection with bereavement has been termed complicated grief or prolonged grief disorder. The purpose of this paper is to analyze the literature on loss and mourning ... to describe the epidemiological and clinical aspects of "normal" and "complicated" grief... [http://www.rivistadipsichiatria.it/r.php?v=1551&a=16903&l=24975&f=allegati/01551_2014_03/fulltext/02-Lombardo%20\(106-114\).pdf](http://www.rivistadipsichiatria.it/r.php?v=1551&a=16903&l=24975&f=allegati/01551_2014_03/fulltext/02-Lombardo%20(106-114).pdf)

N.B. Italian language article.

[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>

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

The presence of hospital-based palliative care programs: A resource dependence perspective

HEALTHCARE MANAGEMENT REVIEW | Online – 10 July 2014 – Hospitals with high Medicare inpatient days, located in counties with high Medicare managed penetration, and larger hospitals had greater odds of having a hospital-based palliative care program. Although hospitals in counties with a high percentage of individuals 65+, for-profit and government hospitals were less likely to have a hospital-based palliative care program. Hospitals will vary in the organizational resources available, as such, administrators' awareness of the relationship between resources and palliative care programs can help determine the relevance of a program in their hospital. http://journals.lww.com/hcmrjournal/Abstract/publishahead/The_presence_of_hospital_based_palliative_care.99858.aspx

Noted in Media Watch, 14 July 2014, #366 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 7 July 2014 – **'End-of-life health care utilization in hospitals with compared to those without palliative care programs.'** Evaluations of palliative care frequently use end-of-life health care utilization as a key outcome. Hospitals that are early adopters of palliative care programs may differ systematically from U.S. hospitals overall factors such as hospital size, ownership, and baseline utilization that may affect programs' effectiveness. The object of this study was to describe key characteristics of U.S. hospitals with early palliative care programs compared with those without, including differences in end-of-life utilization. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0079>

Of related interest:

- *HEALTH SERVICES RESEARCH* | Online – 15 July 2014 – **'Cost savings from palliative care teams and guidance for a financially viable palliative care program.'** The authors found overall cost savings from palliative care of \$3,426 per patient for those dying in the hospital. No significant cost savings were found for patients discharged alive; however, significant cost savings for patients discharged alive could be achieved for certain diagnoses, palliative care team structures, or if consults occurred within ten days of admission. <http://onlinelibrary.wiley.com/doi/10.1111/1475-6773.12203/abstract;jsessionid=BF5BEC71D23EE40222BFC4C7327458DF.f04t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Teleological care and the last years of life

JOURNAL OF EVALUATION IN CLINICAL PRACTICE | Online – 12 July 2014 – Teleological care [TC] is a philosophy of care built around the root idea of a telos (i.e., end) in three senses: 1) the end of life as a temporal limit; 2) the ends of life as the individual's purpose and meaning; and, 3) the end of life as the meaning of life as a whole. In its practice, teleological care adheres to principles of 1) fidelity of practitioner to patient; 2) generalism of practitioners; and, 3) coordination of care within existing services. With this philosophy and practice, care is administered by generalist health care professionals arranging for flow between care that attempts to reverse, stop or slow the disease process when appropriate, with care to address symptoms, and with care that responds to the difficulties of dying. TC involves already existing programs in roughly their present forms, serving as an overarching layer of organization added to the existing systems. It refocuses the concept of care to the patient's perspective with emotional, spiritual and practical support for facing the end of life and a space for narrative and reflection within a wider circle of care. <http://onlinelibrary.wiley.com/doi/10.1111/jep.12211/abstract;jsessionid=E0C5F11A1DD4E4437C4EF2E63C148758.f04t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Cont.

Of related interest:

- *ILLNESS, CRISIS, & LOSS*, 2014;22(7):127-144. '**Life interrupted: The impact of complex chronic disease from the perspective of hospitalized patients.**' [Study] participants' views were organized into six themes: 1) loss of autonomy; 2) meaningful activities; 3) structures of meaning; 4) social fabric; 5) mental health; and, 6) finances. Most participants articulated multiple losses, particularly those with high illness severity. This study sheds light on the experience of loss as a consequence of disease. To adequately support the needs of these individuals, a model of care must address the interface between mental, social, and physical health. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,4,10:journal,1,78;linkingpublicationresults,1:103734,1>
- *MISSOURI MEDICINE*, 2014;111(3):174-179. '**Getting comfortable with death. Palliative care begins at home.**' Palliative care is multidimensional care of patients with life-limiting diseases concurrent with active disease management, together with support for their caregivers. Components of primary palliative care include management of physical and psychological symptoms and discussions about goals of care and end of life wishes. Primary care physicians and all specialty physicians should provide primary palliative care for their chronically ill patients. <http://europepmc.org/abstract/med/25011328>

Australian Chinese patient's experiences of palliative care services

JOURNAL OF GERIATRICS & PALLIATIVE CARE, 2014;2(2). Australia is a multicultural country that consists of a diverse population. It can be difficult to provide equal healthcare services across all ethnicities due to cultural disparities. This is seen amongst Australian Chinese to under-utilize healthcare services such as palliative care. Seven themes were explored. The majority of participants understood the role of palliative care and would accept the service. They favored being informed about the nature of their condition even during advanced stages. Many preferred making decisions for their own treatment but highly valued the advice from doctors and family members. Most participants were open to discuss issues related to death and dying and the need for interpreter services was highlighted. They viewed that nutrition and hydration as necessity during end-of-life and many believed in a combined regimen of western and alternative therapy to treat their condition. This study shows Australian Chinese understand the role of palliative care. Changes in perception in areas such as disclosure of the truth of a disease and openness in discussing issues related to death and dying are highlighted. Traditional Chinese values still play a role in shaping their attitudes regarding decision-making and hydration and nutrition during end-of-life care. <http://www.avensonline.org/wp-content/uploads/2014/06/JGPC-2373-1133-02-0004.pdf>

"Best interests" and withholding and withdrawing life-sustaining treatment from an adult who lacks capacity in the *parens patriae* jurisdiction

JOURNAL OF LAW & MEDICINE, 2014;12(4):920-941. Disputes about withholding and withdrawing life-sustaining treatment are increasingly coming before Australian Supreme Courts. Such cases are generally heard in the *parens patriae* jurisdiction where the test applied is what is in the patient's "best interests." However, the application of the "best interests" test, and its meaning, remains unclear in this context. To shed light on this emerging body of jurisprudence, this article analyses the Australian superior court decisions that consider an adult's best interests in the context of decisions about life-sustaining treatment. The authors identify a number of themes from the current body of cases and consider how these themes may guide future decision-making. After then considering the law in the U.K., they suggest an approach for assessing best interests that could be adopted by Australian Supreme Courts. The authors argue that the suggested approach will lead to a more structured and systematic decision-making process that better promotes the best interests of the patient. <http://eprints.qut.edu.au/73554/2/73554a.pdf>

N.B. *Parens patriae* is Latin for "parent of the nation." In law, it refers to the public policy power of the state to intervene against an abusive or negligent parent, legal guardian or informal caretaker.

Cont.

Of related interest:

- *MULTIDISCIPLINARY RESPIRATORY MEDICINE* | Online – 16 July 2014 – '**On the ethics of withholding and withdrawing medical treatment.**' A general rationale is presented for withholding and withdrawing medical treatment in end-of-life situations and an argument is offered for the moral irrelevance of the distinction, both in the context of pharmaceutical treatments, such as chemotherapy in cancer, and in the context of life-sustaining treatments, such as the artificial ventilator in lateral amyotrophic sclerosis. It is argued that this practice is not equivalent to sanctioning voluntary active euthanasia and that it is not likely to favour it. <http://www.mrmjournal.com/content/pdf/2049-6958-9-39.pdf>

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

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

Clinically assisted hydration and the Liverpool Care Pathway: Catholic ethics and clinical evidence

JOURNAL OF MEDICAL ETHICS | Online – 17 July 2014 – The Liverpool Care Pathway for the Dying Patient (LCP), a framework introduced for providing comfortable care at the last stage of life, has recently become highly contentious. Among the most serious allegations levelled against it, has been that the LCP may be used as a covert form of euthanasia by withdrawal of clinically assisted hydration (CAH). This concern has been raised, in particular by a number of Catholic medical professionals, who have asserted that the LCP is incompatible with Catholic ethics. This paper examines the key Catholic ethical principles relevant to treatment and care towards the end of life (the sanctity/inviolability of life principle, the distinction between ordinary and extraordinary means). Relevant current clinical evidence regarding CAH in relation to terminal thirst, dehydration, prolongation of life and possible negative impacts on the dying is also scrutinised. It is argued that for some patients at the very end of life it may be permissible and even desirable to withhold or withdraw it. Thus, as administration of CAH may become extraordinary, forgoing it in some situations is fully compatible with Catholic ethics. The article therefore concludes that the stance of the LCP in respect of provision of CAH is fully in alignment with Catholic teaching. <http://jme.bmj.com/content/early/2014/07/17/medethics-2013-101533.abstract>

Cultural influences in pediatric cancer from diagnosis to cure/end of life

JOURNAL OF PEDIATRIC ONCOLOGY NURSING | Online – 10 July 2014 – Cultural factors influenced many aspects of the cancer experience including illness representations, reaction to diagnosis, illness disclosure patterns, complementary and alternative medicine use, management of medical procedures, coping strategies, and end of life issues. Increased awareness of cultural factors is needed to improve clinical care and reduce health disparities. Specific strategies to approach cultural differences are provided to enhance patient and family care from diagnosis to cure/end of life. <http://jpo.sagepub.com/content/early/2014/07/01/1043454214529022.abstract>



World hospice &
palliative care day

11 October 2014

Who Cares? We Do!

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

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

Revisiting advance decision making under the [U.K.] Mental Capacity Act 2005: A tale of mixed messages

MEDICAL LAW REVIEW | Online – 12 July 2014 – Most of the literature relating to advance decisions has focused on philosophical questions. This article reflects on the significant legal developments that have occurred since the introduction of the Mental Capacity Act 2005 [and] provides a critique of the controversial issues which have emerged within contemporary case law. <http://medlaw.oxfordjournals.org/content/early/2014/07/12/medlaw.fwu021.abstract>

Awareness of dementia by family carers of nursing home residents dying with dementia: A post-death study

PALLIATIVE MEDICINE | Online – 18 July 2014 – High-quality palliative care for people with dementia should be patient-centered, family-focused, and include well-informed and shared decision-making, as affirmed in a recent white paper on dementia from the European Association for Palliative Care.¹ Family carers are often unaware that their relative has dementia, that is, in one-fourth of cases of dementia and one-fifth of advanced dementia, posing considerable challenges for optimal care provision and end-of-life decision-making. Considering that family carers of residents who develop dementia later after admission to a nursing home are less likely to be aware, there is room for improving communication strategies toward family carers of nursing home residents. <http://pmj.sagepub.com/content/early/2014/07/18/0269216314542261.abstract>

1. 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,' *Palliative Medicine*, 4 July 2013. The first definition of palliative care in dementia and a framework to provide guidance for clinical practice, policy and research. Experts from twenty-three countries evaluated a set of eleven domains and fifty-seven recommendations. [Noted in Media Watch, 8 July 2013, #313 (p.10)] <http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract>

Developing a palliative care service model for Muslim Middle Eastern countries

SUPPORTIVE CARE IN CANCER | Online – 18 July 2014 – Palliative Care (PC) was first introduced to Muslim Middle Eastern (MME) countries in 1992, but growth has been slow and access is still limited. While most PC models have been developed in Western countries, MME societies have different cultural and religious values that are not incorporated in Western models. The authors conducted a study to look at these differences, in order to inform a culturally acceptable model of PC that meets the needs of MME patients and their families. They identified a number of important differences in PC practice, as well as common barriers and facilitators for developing PC services in MME countries. <http://link.springer.com/article/10.1007/s00520-014-2347-4>

Noted in Media Watch, 24 February 2014, #346 (p.8):

- *AFRICAN HEALTH SCIENCES*, 2013;13(4):893-898. '**Care of terminally-ill patients: An opinion survey among critical care healthcare providers in the Middle East.**' The authors studied the effect of training background and seniority on do not resuscitate (DNR) decisions in the Middle East. Most of the responders to an anonymous questionnaire were Muslim (86%) and consultants (70.9%). The majority were trained in western countries. Religion played a major role in 59.3% for making the DNR decision. DNR was considered equivalent to comfort care by 39.5%. In a futile case scenario, do not escalate therapy was preferred. The likelihood of a patient, once labeled DNR, being clinically neglected was a concern among 46.5%. Admission of DNR patients to the ICU was acceptable for 47.7%. Almost one-half of the responders (46.5%) wanted physicians to have the ultimate authority in the DNR decision. Training background was a significant factor affecting the interpretation of the term no code DNR. <http://www.ajol.info/index.php/ahs/article/viewFile/100195/89457>

Cont.

Noted in Media Watch, 10 June 2013, #309 (p.15):

- *JOURNAL OF PALLIATIVE CARE MEDICINE* | Online – Accessed 6 June 2013 – '**Palliative care training gains ground in Middle Eastern countries.**' The responses and observations gleaned from two American Society of Clinical/Middle East Cancer Consortium workshops in the Middle East provide further support for the notion that additional efforts are needed to improve the management of cancer-related physical and emotional symptoms by means of ongoing training sessions for all care givers, in particular physicians and nurses, as has been recently advocated. <http://www.omicsgroup.org/journals/2165-7386/2165-7386-S3-e001.pdf>

Making sense of continuous sedation in end-of-life care for cancer patients: An interview study with bereaved relatives in three European countries

SUPPORTIVE CARE IN CANCER | Online – 15 July 2014 – Relatives' descriptions of the practice referred to the outcome, to practical aspects, and to the goals of sedation. While most relatives believed sedation had contributed to a "good death" for the patient, yet many expressed concerns. These related to anxieties about the patient's wellbeing, their own wellbeing, and questions about whether continuous sedation had shortened the patient's life (mostly in the U.K.), or whether an alternative approach would have been better. Such concerns seemed to have been prompted by relatives witnessing unexpected events such as the patient coming to awareness during sedation. In The Netherlands and in Belgium, several relatives reported that the start of the sedation allowed for a planned moment of "saying goodbye." In contrast, U.K. relatives discerned neither an explicit point at which sedation was started nor a specific moment of farewell. <http://link.springer.com/article/10.1007/s00520-014-2344-7>

[Media Watch: Editorial Practice](#)

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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.

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY* | Online – 10 July 2014 – '**Assisted dying in dementia: A systematic review of the international literature on the attitudes of health professionals, patients, carers and the public, and the factors associated with these.**' Health professionals hold more restrictive views towards assisted dying, which appear less affected by their cultural background, than the public, patients and carers. However, opinions within each population vary according to dementia severity and issues of capacity, as well as differing according to factors such as age, ethnicity, gender and religion of those surveyed. There also appears to be a trend towards more accepting attitudes over time. <http://onlinelibrary.wiley.com/doi/10.1002/gps.4169/abstract;jsessionid=643ABBEF2FDBDC42A01816544B08294A.f03t01?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/5/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.htm> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

Asia

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

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

Australia

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

Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://www.hpcconnection.ca/newsletter/inthenews.html>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to 'Additional Resources']

Europe

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

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

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

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