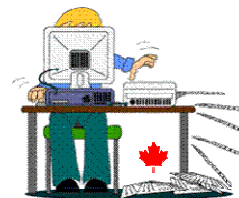


Media Watch...

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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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

Compiled & Annotated by Barry R. Ashpole

A duty to care? – Scroll down to [Specialist Publications](#) and 'Till death us do part? A critical analysis of obligation and choice for spousal caregivers' (p.9), in *Journal of Gerontological Social Work*.

U.S.A.

Scientists seek to rein in diagnoses of cancer

THE NEW YORK TIMES | Online – 29 July 2013 – A group of experts advising the nation's premier cancer research institution has recommended changing the definition of cancer and eliminating the word from some common diagnoses as part of sweeping changes in the nation's approach to cancer detection and treatment. The recommendations [are] from a working group of the National Cancer Institute.¹ They say, for instance, that some premalignant conditions, like one that affects the breast called ductal carcinoma in situ, which many doctors agree is not cancer, should be renamed to exclude the word carcinoma so that patients are less frightened and less likely to seek what may be unneeded and potentially harmful treatments that can include the surgical removal of the breast. <http://well.blogs.nytimes.com/2013/07/29/report-suggests-sweeping-changes-to-cancer-detection-and-treatment/?ref=health&r=0>

1. 'Over diagnosis and overtreatment in cancer: An opportunity for improvement,' *Journal of the American Medical Association*, 29 July 2013. The recommendations of the task force are intended as initial approaches. <http://jama.jamanetwork.com/article.aspx?articleid=1722196>

Specialist Publications

'End-of-life care in Toronto [Canada] neonatal intensive care units: Challenges for physician trainees' (p.6), in *Archives of Disease in Childhood: Fetal & Neonatal Edition*.

'The standard of care and conflicts at the end of life in critical care: Lessons from medical-legal crossroads and the role of a quasi-judicial tribunal [i.e., Ontario's Consent & Capacity Board] in decision-making' (p.9), in *Journal of Critical Care*.

'Informed consent and patient comprehension: The law [in Canada] and the evidence' (p.9), in *McGill Journal of Law & Health*.

Media Watch Online

Media Watch (or a link to the weekly report) is posted on several websites that serve the hospice and palliative care community-at-large. See a complete listing on p.13.

Physician Orders for Life-Sustaining Treatment

A new approach to end-of-life directives

FLORIDA | *The Herald-Tribune* (Sarasota) – 28 July 2013 – Even for the 29% of Americans who have filled out basic legal paperwork to make their final wishes known, a drawn-out, undignified and uncomfortable hospital death remains all too possible, medical policy specialists admit. And, for the remaining 71%, such an end is even more likely. "In many respects we've been doing a really bad job with end-of-life care, and we've done that for a long time," says Kenneth Goodman, director of the University of Miami's bioethics program. So after decades of struggle to improve end-of-life care, and to give patients' wishes some power over the long reach of medical technology, an increasing number of U.S. health care professionals are supporting a new way to slice through the confusion, pain and sadness that can surround a hospital or nursing home death. The emerging solution is a medical order form that instructs health pro-

viders to honor a patient's wishes – ranging from simple comfort care to the most intense and heroic measures. The document, originating in Oregon, is known as a POLST. <http://www.heraldtribune.com/article/20130728/ARTICLE/130729678/2055/NEWS?Title=NEW-A-new-approach-to-end-of-life-directives>

Specialist Publications

'Is hospice care dying in the U.S.?' (p.12), in *International Journal of Palliative Nursing*.

'A nudge in the right direction with a stick the size of CMM [Centers for Medicare & Medical Services]: Physician-patient communication at the end of life' (p.11), in *Saint Louis University Journal of Health Law & Policy*.

Noted in Media Watch, 20 May 2013, #306 (p.13):

- *THE LINACRE QUARTERLY*, 2013;80(2):103-138. **'The POLST paradigm and form: Facts and analysis.'** This white paper provides a commentary on Physician Orders for Life-Sustaining Treatment as well as on its model (or "paradigm") for implementation across the U.S. <http://www.ingentaconnect.com/content/maney/lnq/2013/00000080/00000002/art00002>

International

In Ukraine, a new way of looking at pain – and death

UKRAINE | Radio Free Europe – 4 August 2013 – Ukraine this year became the first in the region to legalize better access to strong pain medication for patients dying from cancer, AIDS, and other incurable illnesses. Diederik Lohman, at Human Rights Watch, says the measure is a victory for terminally ill patients who previously faced the prospect of enduring a slow, painful death at home. "There was a point where their doctors would say, 'Well, there's nothing we can do for you anymore, because you failed third-line cancer treatment, or the antiretroviral drugs aren't working, or you have incurable [tuberculosis],' and those patients would often just be sent home with [the message], 'There's nothing the medical system can do for you, so go home and die,'" Lohman says. Patients in Ukraine have long had controlled access to certain strong opioids like liquid morphine. But fears about drug abuse meant the process for obtaining the medication was bogged down by bureaucracy and long waits. <http://www.rferl.org/content/ukraine-pain-management-cancer-suffering/25059851.html>

Cont.

Noted in Media Watch, 20 May 2013, #306 (p.6):

- UKRAINE | Reuters – 15 May 2013 – **'New breakthrough for incurably ill.'** Ukraine's cabinet of ministers' approval of new regulations on access to pain medicines will dramatically expand healthcare services for patients with incurable illnesses and reduce unnecessary suffering. A Human Rights Watch report in 2011 concluded that tens of thousands of cancer patients in Ukraine die every year in severe pain because they cannot get adequate palliative care services.¹ <http://www.trust.org/item/20130515040000.0000-g96tq/>

1. *Uncontrolled Pain: Ukraine's Obligation to Ensure Evidence-Based Palliative Care*, Human Rights Watch, 12 May 2011. [Noted in Media Watch, 16 May 2011, #201 (p.4)] <http://www.hrw.org/en/reports/2011/05/12/uncontrolled-pain-0>

End-of-life care in China

Living will registration stirs dignified death debate

CHINA | Xinhua News Agency – 1 August 2013 – A newly-established association advocating living will registration has triggered debate on death with dignity, with many hoping the organization can help preserve patients' rights in terms of receiving life-prolonging treatments. The Beijing Living Will Promotion Association, approved by the Beijing Civil Affairs Bureau, gathered more than 20 medical experts to discuss the necessity of living wills and how to promote the idea of death with dignity in China. There are no clinical regulations to define when doctors should stop carrying out treatment after patients enter an unconscious state, even if they have agreed to give up treatment previously in a living will. In addition, laws or regulations have never been created to protect patients' living wills, an oversight which experts believe is a potential breeding ground for doctor-patient disputes. According to a survey by the China Hospital Management Association, medical-treatment disputes have seen an average 23% rise year on year since 2002. Experts agreed that it's necessary to popularize living will registration and legalize its implementation, as it can not only respect patients' wishes and bring dignity to their passing, but also help reduce doctor-patient mistrust. http://news.xinhuanet.com/english/china/2013-08/01/c_132594452.htm

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

New report finds half of dying Britons are not dying well

U.K. | Compassion in Dying – 1 August 2013 – A new report finds almost half of those who have lost someone close to them through a short or long illness, feel their loved one died badly (45%).¹ In cases where the dying person had recorded their end of life wishes, relatives and friends are more likely to report they had a good death (58%). Alongside recording end of life wishes (19%), better communication between the doctor and their loved one (39%), co-ordination of care (33%) and being able to die in a place of their choice (31%) were also identified as key aspects which could have improved the situation for the person who died in a bad way. With the recent decision to replace The Liverpool Care Pathway

with personalised care plans ... this report reinforces the importance of advance care planning at the end of life and the urgent need to put in place workable guidance... <http://www.compassionindying.org.uk/01-august-2013-press-release-new-report-finds-half-dying-britons-are-not-dying-well>

Specialist Publications

'Coordination of care for individuals with advanced progressive conditions: A multi-site ethnographic and serial interview study' (p.7), in *British Journal of General Practice*.

1. *Divided in Dying*, Compassion in Dying, August 2013. <http://www.compassionindying.org.uk/sites/default/files/2013-08-01%20-%20Divided%20in%20Dying%20-%20Final.pdf>

Cont.

Of related interest:

- U.K. (ENGLAND) | *The Northamptonshire Telegraph* – 31 July 2013 – **'Health bosses insist hospices won't close.'** Health bosses have insisted two Northamptonshire hospices won't close following reports of cuts, but they confirmed plans to increase charitable donations with a view to reducing National Health Service [NHS] funding [see sidebar]. Initial figures published by the Nene & Corby Clinical Commissioning Group suggested Cransley Hospice and Cynthia Spencer Hospice could have their funding cut by £2million over the next two to three years; this figure has since been withdrawn. The commissioning group, which has an annual budget of £653million, would like to see the hospices' funding more like that of the majority of hospices in the country, with 70% raised through charitable means and 30% given by the NHS. <http://www.northantstelegraph.co.uk/news/top-stories/health-bosses-insist-hospices-won-t-close-1-5338368>

Noted in Media Watch, 24 June 2013, #311 (p.6):

- U.K. (ENGLAND) | Help the Hospices – 18 June 2013 – **'Hospices losing out under complex new commissioning arrangements.'** Hospices across England are caught in "a cat's cradle" of complex commissioning and contracting arrangements under new National Health Service structures ... hindering hospices and saddling many with additional costs. <http://www.helpthehospices.org.uk/media-centre/press-releases/hospices-losing-new-commissioning-arrangements/>

End-of-life care in India

The amended narcotic drugs law must be passed soon as more effective palliative care for cancer patients hinges on it

INDIA | *The Hindu* (OpEd) – 31 July 2013 – Where there is pain, no head can be held high. We used to witness this every day as our teams travelled from door-to-door and from patient-to-patient bringing succour and relief to those facing the challenge of an advancing cancer. It was always about pain! Here was someone crouched in a corner on the floor, there was someone else banging his head against the wall, and yet another being held down by distraught relatives as he thrashed about like a fish on a hook. Small wonder then that as they went about their tasks, our teams began to suffer burnout born out of a sense of helplessness in the face of such great suffering. All of this changed after we got our licence for oral morphine and could now assure our patients that their physical pain would no longer hold them captive. Sadly, there are millions in India today who are not as lucky. They have been denied freedom from pain because of out-dated and onerous regulations which were brought in by the British and continue to this day in spite of advances in medicine. This is the state of affairs that shames all of us who work in the field of palliative care in this country. We, too, cannot hold our heads up high anywhere. A few months ago we were so hopeful that this would finally change. The Revenue Ministry ... amended the Narcotic Drugs & Psychotropic Substances Bill so that access to oral morphine for pain control would no longer be the prerogative of a lucky few. But I am afraid that our hopes were belied when the amended Bill in its latest version was not passed in the last session of Parliament... It has left us wondering whether the Bill will be tabled and passed in the coming session or not so that India can finally join the comity of civilized nations and can show through its actions that it cares for the well-being of its citizens. <http://www.thehindu.com/opinion/op-ed/nursing-the-morphine-dream/article4971105.ece?homepage=true>

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>

Elder care in Scotland

New figures show cost of home care risen by 160% in less than a decade

U.K. (SCOTLAND) | *The Herald* (Glasgow) – 30 July 2013 – The cost of providing free personal care for people living at home has increased by around 160% in less than a decade, new figures show. Councils spent a total of £346.7million in 2011-2012, compared with £132.8million in 2003-2004. The 161% increase is said to be in part due to a shift away from providing care for elderly people in care homes. The figures from the Scottish Government also show an increase in the number of hours of care being provided. Across Scotland an average of 381,700 hours of free personal care were provided to people in their own homes in each week of 2011-2012, a substantial increase from the average of 226,000 hours a week in 2003-2004. The average amount of care received per person has also risen by more than an hour over the period, from 6.9 hours to 8.2 hours, suggesting that people receiving care at home have increasing levels of need. The number of people receiving free personal care in their home increased from 32,870 in 2003-2004 to 46,740 in 2011-2012. Before July 2002 people could be charged when they received personal care services, such as help with washing, dressing and eating. The introduction of the policy meant people 65 and over could no longer be charged for receiving this help in their own home. <http://www.heraldscotland.com/news/home-news/new-figures-show-cost-of-home-care-risen-by-160-in-less-than-a-decade.1375188465>

Of related interest:

- U.K. (ENGLAND) | *The Guardian* – 29 July 2013 – **'Homecare providers have plenty of creative ideas for improving care.'** The relentless negative media would have us believe that callousness, carelessness and unreliability are the norm in homecare. This is fundamentally wrong and deeply unfair to hard working, caring homecare workers, and it does real damage to the confidence of those who might need support and their families and friends who are considering care options. The numbers tell us that demand for this life-enriching service is constantly growing; there are 4.3 million over 75s today, and this is predicted to rise to 7.34 million in 2033; there are 800,000 people living with dementia now, rising to over a million in 2021. <http://www.theguardian.com/social-care-network/2013/jul/29/homecare-providers-ideas-improving-care>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. (ENGLAND & WALES) | Reuters – 31 July 2013 – A British court rejected appeals for the right to die by a paralysed road accident victim and the family of a deceased locked-in syndrome sufferer, saying only parliament should decide on matters of life and death. The Court of Appeal said the law on assisted suicide could not be changed by the courts, quashing the appeal by paralysed man Paul Lamb and the family of Tony Nicklinson, who suffered locked-in syndrome, where someone is aware and awake but cannot move or communicate. <http://uk.reuters.com/article/2013/07/31/uk-britain-rights-suicide-idUKBRE96U0KK20130731>

Noted in Media Watch, 22 April 2013, #302 (p.6):

- U.K. | BBC News – 18 April 2013 – **'Right to die debate.'** Paul Lamb is the latest person to seek a change in the law so that he can be allowed to die with the help of a doctor.¹ His case continues the same legal challenge mounted by the late Tony Nicklinson, who also wanted the right to seek medical assistance to end his life. These cases go beyond those of Diane Pretty and Debbie Purdy, who wanted to challenge laws on "assisted suicide" – to protect their husbands if they helped them to die. <http://www.bbc.co.uk/news/health-22198464>

1. 'Right to die: Paul Lamb takes up Tony Nicklinson's fight,' BBC News, 18 April 2013. <http://www.bbc.co.uk/news/uk-22191059>

N.B. Links to reports pertaining to Nicklinson, Pretty and Purdy are embedded in the BBC report.

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

What is the evidence base for electronic medical records improving quality in hospice and palliative medicine?

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 28 July 2013 – As with health care providers in general, those of us in hospice and palliative medicine have been rather forcibly compelled to adopt the use of electronic medical records (EMRs). Indeed, as of 5 years ago, nearly half of all home health hospice care providers were using EMRs, which has likely increased since that time. The U.S. federal government has invested tremendous resources toward influencing not only acute care hospitals and physicians but also home health and hospice services to broadly adopt the use of EMR systems. Yet, what is evidence base that our government is using to compel us to wholeheartedly embrace EMR? The answer, quite frankly, is precious little. <http://ajh.sagepub.com/content/early/2013/07/26/1049909113496867.extract>

Of related interest:

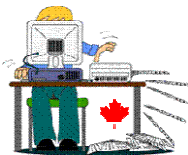
- *PATIENT EDUCATION & COUNSELING* | Online – 31 July 2013 – **'Connecting with patients and instilling realism in an era of emerging communication possibilities: A review on palliative care communication heading to telecare practice.'** This review aims at describing communication patterns in palliative care and discussing potential relations between communication patterns and upcoming telecare in the practice of palliative care. This review includes 71 articles. [http://www.pec-journal.com/article/S0738-3991\(13\)00277-2/abstract](http://www.pec-journal.com/article/S0738-3991(13)00277-2/abstract)

End-of-life care in Toronto [Canada] neonatal intensive care units: Challenges for physician trainees

ARCHIVES OF DISEASE IN CHILDHOOD: FETAL & NEONATAL EDITION | Online – 30 July 2013 – [Study] participants identified six domains of challenge in EOL [end of life] care: 1) withdrawal of life-sustaining treatment based on poor outcome 2) explaining "no resuscitation options" to parents; 3) clarifying "do not resuscitate" (DNR) orders; 4) empowering families with knowledge and shared decision-making; 5) dealing with different cultures; and, 6) managing personal internal conflict. Participants experienced the most difficulty during the initial stages of training and eventually reported good knowledge of the EOL care process. They had a sense of security and confidence working within a multidisciplinary care team, which includes experienced nursing staff as well as bereavement and palliative care coordinator within the neonatal intensive care unit. <http://fn.bmj.com/content/early/2013/07/30/archdischild-2012-303000.abstract>

Noted in Media Watch, 3 December 2012, #282 (pp.13-14):

- *SEMINARS IN FETAL & NEONATAL MEDICINE* | Online – 22 November 2012 – **'Evidence-based comfort care for neonates towards the end of life.'** When examining the evidence base for most interventions, it is lacking – but this is not unique to this aspect of neonatal care. Clinicians can acknowledge that patient needs require managing their end-of-life symptoms now; neither these patients nor their families should have to wait for research to catch up to their current needs. <http://www.sciencedirect.com/science/article/pii/S1744165X1200131X>



Barry R. Ashpole

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

Referral to palliative care

Coordination of care for individuals with advanced progressive conditions: A multi-site ethnographic and serial interview study

BRITISH JOURNAL OF GENERAL PRACTICE, 2013;63(613):e580-e588. Very few [study] participants had been identified for a palliative approach. Rapid throughput of hospital patients and time pressures in primary care hindered identification of palliative care needs. Lack of care coordination was evident during emergency admissions and discharges. Patient, families, and professionals identified multiple problems relating to lack of information, communication, and collaboration at care transitions. Family carers or specialist nurses, where present, usually acted as the main care coordinators. Care is poorly coordinated in generalist settings for patients in the last year of life, although those with cancer have better coordinated care than other patients. A model to improve coordination of care for all individuals approaching the end of life must ensure that patients are identified in a timely way, so that they can be assessed and their care planned accordingly. <http://www.ingentaconnect.com/content/rcgp/bjgp/2013/00000063/00000613/art00040>

Of related interest:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2013;19(7):315. **'One feature common to all models of palliative care.'** At the recent European Association of Palliative Care World Congress, a theme common to many of the posters was "models of care." Posters from around the world, including India, Romania, Australia, Switzerland, Argentina, Kenya, Malawi, China, Spain, and the U.S. discussed different aspects of a model of palliative care. Some of the papers looked at an overall model of care, whereas others discussed specific aspects such as spirituality, breathlessness, resilience, and communication. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=100004;article=IJPN_19_7_315
- *MAYO CLINIC PROCEEDINGS*, 2013;88(8):859-865. **'Top 10 things palliative care clinicians wished everyone knew about palliative care.'** This article discusses the changing role of modern palliative care, addresses common misconceptions, and presents an argument for early integration of palliative care in the treatment of patients dealing with serious illness. [http://www.mayoclinicproceedings.org/article/S0025-6196\(13\)00452-7/abstract](http://www.mayoclinicproceedings.org/article/S0025-6196(13)00452-7/abstract)

Do patients die well in your emergency department?

EMERGENCY MEDICINE AUSTRALASIA | Online – 25 July 2013 – Of 165 eligible ED directors, 35 completed the survey. Only 49% believed that ED provided good palliative care, and 80% were unaware of international gold standard palliative care protocols. Most had access to hospital-based palliative care specialists (77%); however, only 19% used them. Few EDs undertake formal training in palliative care (29%). Although limited by the low response rate, this survey indicates that there is a need and a desire for greater integration of the values and standards of high-quality palliative care in Australasian EDs. <http://onlinelibrary.wiley.com/doi/10.1111/1742-6723.12099/abstract;jsessionid=BF3EB5C23715B5BCDC40C9E6BBA8E026.d04t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

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

- *PALLIATIVE CARE & MEDICINE* | Online – Accessed 2 July 2013 – **'When end-of-life care is the emergency: A case-based portrayal of end-of-life care in the emergency department.'** This article reviews why EDs are a necessary and important place for end-of-life (EOL) discussions and management, and highlight real-life cases in which the ED team played an integral role in identifying appropriate patients for EOL care and providing these services. <http://www.omicsgroup.org/journals/2165-7386/2165-7386-3-146.pdf>

Cont.

Noted in Media Watch, 4 June 2012, #256 (p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE* | Online – 23 May 2012 – **'Why do palliative care patients present to the emergency department? Avoidable or unavoidable?'** With an understanding of why patients present, interventions to avoid these presentations close to the end-of-life may be possible. A comprehensive, coordinated approach across community and acute services may help ensure patients are not sent to the ED inappropriately. <http://ajh.sagepub.com/content/early/2012/05/18/1049909112447285.abstract>

N.B. Noted in Media Watch, 16 July 2012, #262 (p.6), are several articles from past issues of the weekly report on the provision and delivery of palliative care in the emergency department.

Insight into African American culture

Barriers to using palliative care

JOURNAL OF CLINICAL ONCOLOGY NURSING, 2013;17(4):376-380. This article highlights barriers associated with the under enrollment of African Americans into hospice and palliative care programs. An analysis of the literature was conducted to define hospice and palliative care and assess circumstances that impact the use of hospice services by African Americans. Many ... are not choosing hospice care because of cultural issues or knowledge deficits, whether through lack of communication or low literacy. Healthcare providers can begin by familiarizing themselves with hospice organizations and developing and putting into practice strategies to communicate with and educate patients and families about hospice care in a culturally sensitive manner. <http://ons.metapress.com/content/j550722676r7q431/?p=9d0f4a82a2854c11b33df180c433eadf&pi=6>

Noted in Media Watch, 4 June 2012, #303 (p.6):

- *JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED*, 2012;23(1):28-58. **'What influences African American end-of-life preferences?'** Many African Americans choose aggressive life-sustaining treatment at the end of life, even if that treatment seems likely to confer great burden with little chance of benefit. The reasons are multi-faceted and include knowledge of/access to services, historical mistrust of the health care system, and spiritual beliefs. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/journal_of_health_care_for_the_poor_and_underserved/v023/23.1.wicher.html

Noted in Media Watch, 7 May 2013, #252 (p.9):

- *HOWARD JOURNAL OF COMMUNICATION* | Online – 27 April 2012 – **'African Americans and decisions about hospice care: Implications for health message design.'** Many scholars have identified the barriers that may limit hospice enrollment and have called for the development of outreach campaigns to educate African Americans about hospice services. The design and implementation of such campaigns requires that campaign planners understand the issues that are most relevant to African American patients and families in making decisions about hospice care. <http://www.tandfonline.com/doi/abs/10.1080/10646175.2012.667724>

Developing understanding of same sex partner bereavement for older lesbian and gay people: Implications for social work practice

JOURNAL OF GERONTOLOGICAL SOCIAL WORK | Online – 22 July 2013 – There is little research and literature exploring same sex partner bereavement in later life or end of life experiences of lesbian and gay elders in the U.K. This paper considers this often overlooked area of social work practice and explores a range of factors emerging from a small explorative study which considers the experience of loss and bereavement for lesbian and gay elders. <http://www.tandfonline.com/doi/abs/10.1080/01634372.2013.825360>

Cont.

Noted in Media Watch, 11 March 2013, #296 (p.8):

- *JOURNAL OF LGBT ISSUES IN COUNSELING*, 2013;7(1):87-116. **'Disenfranchised grief among lesbian and gay bereaved individuals.'** Experiences of grief among lesbian and gay (LG) individuals who have encountered the death of their partner remain invisible within the larger culture and within the counseling literature. This contribution provides a conceptual review of literature regarding the bereavement process of individuals who identify as sexual minorities. <http://www.tandfonline.com/doi/abs/10.1080/15538605.2013.758345>

Till death us do part? A critical analysis of obligation and choice for spousal caregivers

JOURNAL OF GERONTOLOGICAL SOCIAL WORK | Online – 22 July 2013 – Research demonstrates a significant number of carers identify obligation or lack of other alternatives as the reasons they undertake informal care. By utilising critical discourse analysis, this research explores choice for informal caregivers in contemporary Australian social policy. Analysis demonstrates increasing shifts in policy toward choice in consumer directed care, a feature absent for those who provide care. Familial care is a central pillar of Australian social policy, as it is in many liberal and conservative welfare regimes. Analysis reveals that these core social policies are fundamentally incongruent, with significant implications for individuals and social work practice. <http://www.tandfonline.com/doi/full/10.1080/01634372.2013.823472>

Noted in Media Watch, 22 November 2010, #176 (p.9):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 5 October 2010 – **'Filial obligations to elderly parents: A duty to care?'** A continuing need for care for elderly, combined with looser family structures prompt the question what filial obligations are. Do adult children of elderly have a duty to care? <http://www.springerlink.com/content/31gm453171151377/>

Informed consent and patient comprehension: The law [in Canada] and the evidence

MCGILL JOURNAL OF LAW & HEALTH, 2013;7(1):123-128. Few areas of health law attract as much attention as informed consent. In Canada, several well-known Supreme Court cases, and, in some provinces, health care consent laws, provide that physicians must obtain the informed consent of patients prior to providing medical treatment. While the basic parameters of informed consent law are clear, confusion remains about the extent of the duty of physicians to ensure that patients understand the information provided. The need for patient comprehension is self-evident: providing patients with information facilitates decision making and promotes autonomy only if patients are able to understand that information. However, it may be challenging for physicians in practice to meet legal or ethical obligations to ensure patient comprehension, as evidence suggests that many patients do not understand complex medical information or risk information. Reviewing relevant jurisprudence and professional ethics, we examine the nature of this obligation, followed by a discussion of empirical evidence relating to patient comprehension. Based on this review, the authors suggest that there is a disconnect between what the law expects and what patients experience during the informed consent process. http://mjlh.mcgill.ca/pdfs/vol7-1/vol7_issue1_Burningham.pdf

Of related interest:

- *JOURNAL OF CRITICAL CARE* | Online – 25 July 2013 – **'The standard of care and conflicts at the end of life in critical care: Lessons from medical-legal crossroads and the role of a quasi-judicial tribunal in decision-making.'** The results [of this study] reveal some key problems in recourse to the [Ontario] Consent & Capacity Board for clinicians, patients and substitute decision makers in such conflict situations. This study can help improve decision-making by debunking myth of variability in determinations of medical benefit and the standards of care at end of life and reveal the pitfalls of legal recourse in resolving intractable conflicts. <http://www.sciencedirect.com/science/article/pii/S0883944113001913>

Cont.

Noted in Media Watch, 17 December 2012, #284 (p.10):

- *JOURNAL OF CRITICAL CARE*, 2013;28(1):22-27. **'Best interests at end of life: An updated review of decisions made by the Consent & Capacity Board of Ontario.'** There was a significant increase (235%) in decisions from this tribunal between 2009 and 2011. Substitute decision makers rely on an appeal to their own values or religion in their interpretation of best interests; physicians rely on clinical conditions; board emphasizes alignment with Health Care Consent Act. [<http://www.sciencedirect.com/science/article/pii/S0883944112003152>]

Building Momentum: The Science of End-of-Life and Palliative Care: A Review of Research Trends and Funding, 1997-2010

NATIONAL INSTITUTE OF NURSING RESEARCH (U.S.) | Online – This report looks at the trends in end-of-life and palliative care research over the past 14 years. It addresses the 1997 Institute of Medicine recommendations for the scientific community to strengthen the research landscape, foster new evidence and define and implement priorities for increasing the knowledge base for EOL PC. <http://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/NINR-Building-Momentum-508.pdf>

The experiences, coping mechanisms and impact of death and dying on palliative medicine specialists

PALLIATIVE & SUPPORTIVE CARE | Online – 4 August 2013 – This study contributes to the understanding of the impact of death and dying on professionals who care for dying patients and their families. Despite the stressors and potential for burnout and compassion fatigue, participants employed strategies that enhanced meaning-making and emphasized the rewards of their work. The consequences of work stressors cannot be underestimated in the practice of palliative care. <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8936522&fulltextType=RA&fileId=S1478951513000138>

Cont. next page.

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy and research tool.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Of related interest:

- *NEW ENGLAND JOURNAL OF MEDICINE*, 2013;369(5):404-405. **'Mourning on morning rounds.'** Many medical trainees feel sadness, guilt, and a sense of personal failure when a patient dies. But rounds must go on, usually affording no time to pause for reflection. How can one learn to deal with losses of this magnitude without becoming callous and detached? <http://www.nejm.org/doi/full/10.1056/NEJMp1300969>

The Roma family in the context of terminal illness

POSTMODERN OPENINGS, 2013;14(1):73-86. The whole existence of the Roma, regardless of the particularities of their lineage, is modulated by their ancestral culture, which implies respect for the family and the community. The Roma family is usually extended, offers support to its members in any situation and represents the basic unit of the society. The authors present the results of a study that aimed to describe the attitudes, behavior, opinions, beliefs, knowledge and values of Roma that face incurable diseases from two communities in ... Romania, Iasi and Cluj. <http://www.cceol.com/aspx/issuedetails.aspx?issueid=95aafe14-2eac-417d-96d5-915afa52659f&articleid=99e528a4-e4dd-47f3-a9d2-2739d925f4c3>

Noted in Media Watch, 5 November 2013, #278 (p.10):

- *JOURNAL OF IMMIGRANT & MINORITY HEALTH* | Online – 25 October 2012 – **'Dying and death in some Roma communities: Ethical challenges.'** Five important themes ... have been identified: 1) the perception of illness in the community as reason for shame and the isolation that results from this, as well as the tendency for Roma people to take this on in their self image; 2) the importance of the family as the major support for the ill/dying individual, including the social requirement that family gather when someone is ill/dying; 3) the belief that the patient should not be told his/her diagnosis for fear it will harm him/her and that the family should be informed of the diagnosis as the main decision maker regarding medical treatment; 4) the reluctance of the Roma to decide on stopping life prolonging treatment; and, 5) the view of death as "impure." <http://www.springerlink.com/content/f6494wu42j22427h/>

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

A nudge in the right direction with a stick the size of CMM [Centers for Medicare & Medical Services]: Physician-patient communication at the end of life

SAINT LOUIS UNIVERSITY JOURNAL OF HEALTH LAW & POLICY, 2013;6(2):389-423. This paper examines the physician-patient relationship at the end of life and recommends a change to the hospital Medicare Conditions of Participation to remedy many palliative care failures. Most individuals will rely on palliative care at some point in their lives, likely in the form of hospice at the end of life. However, the promise palliative care provides to patients and caregivers has been broken. Perverse Medicare hospice benefits have led to a rise in a for-profit hospice industry, questionable quality, and either very long or very short stays. Additional end-of-life breakdowns occur in the areas of physician-patient communication and pain management. Two states, California and New York, have passed right-to-know statutes requiring physicians to speak with patients about end of life treatment. Other states are considering following suit and the Uniform Law Commission has considered, and rejected, a right-to-know uniform act proposal. However, questions remain about the enforceability of the acts and after which state's statute the uniform act might be modeled. This paper suggests that a federal solution would provide a sweeping and uniform solution to the problem of physician-patient communication. A federal legislative solution seems unlikely given the burden of passing a bill in Congress. Instead, CMS should consider revising the hospital Conditions of Participation to encourage physicians to speak with their patients about end-of-life treatment. http://slu.edu/Documents/law/SLUJHP/Ledden_Article.pdf

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Noted in Media Watch, 15 July 2013, #314 (p.7):

- *THE HASTINGS REPORT*, 2013;43(4):20-28. **'Avoiding a "death panel" redux.'** If engaging in end-of-life conversations and advance care planning not only is desired by many Americans but also might significantly improve patient care at the end of life, then why was a provision that provided reimbursement for physicians to engage in end-of-life planning through Medicare removed from legislation? If ... reimbursements under Medicare "would have been a start" for encouraging these conversations, then why was the Advance Care Planning Consultation provision in the 2008 health reform effort so vehemently opposed by politicians and citizens alike? <http://onlinelibrary.wiley.com/doi/10.1002/hast.190/abstract>

Of related interest:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2013;19(7):316-317. **'Is hospice care dying in the U.S.?'** The Affordable Care Act has three aims: to expand the coverage, control the costs, and improve the delivery of care. With the reform come major financial, regulatory, legislative, and other significant threats to the U.S. hospice and end-of-life care model. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=100008;article=IJPN_19_7_316_317

Paediatric palliative care

The Big Study: For Life-Limited Children and their Families

TOGETHER FOR SHORT LIVES (U.K.) | Online – 29 July 2013 – Findings suggest many of the claims about networks that appear in the policy and management literature are justified, at least in this case. Respondents described ways in which they had benefitted from membership of the network; few reported any disadvantages apart from the time required to be a member. This study could contribute not only to the development of this network [but] to the development of networks in other areas of healthcare. Further analyses of data will investigate what they can tell about the links between and among organisations involved in paediatric palliative care in the West Midlands as well as the distinctive roles nurses and doctors occupy in the network structure. http://www.togetherforshortlives.org.uk/assets/0000/4435/TfSL_The_Big_Study_Final_Research_Report_WEB_.pdf

Of related interest:

- *AMERICAN ACADEMY OF PEDIATRICS*, 2013;34(8):14. **'Health reform law allows children in hospice to be treated for their disease.'** For decades, children with life-threatening or life-span-shortening conditions, faced difficult choices. If they continued to receive disease-related curative or life-prolonging therapy, they were not eligible for hospice services. The Affordable Care Act eliminated this draconian dilemma with the Concurrent Care for Children requirement. <http://aapnews.aappublications.org/content/34/8/14.1.extract>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 July 2013 – **'Predictors of symptoms and site of death in pediatric palliative patients with cancer at end of life.'** Parental choice of aggressive chemotherapy and more aggressive treatment proximal to death predicted more pain, dyspnea, and death in hospital. Strategies to improve quality of life are needed. [In this study] the authors included 61 pediatric palliative patients with cancer whose parents previously participated in a study that elicited preferences for aggressive chemotherapy versus supportive care alone and who subsequently died. <http://ajh.sagepub.com/content/early/2013/07/29/1049909113497419.abstract>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 July 2013 – **'Did increased availability of pediatric palliative care lead to improved palliative care outcomes in children with cancer?'** [In this study] while the location of care during the end-of-life period shifted (from hospital to home), there remains substantial work to ease the suffering in children with cancer at end of life. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0014>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *EUROPEAN JOURNAL OF SCIENCE & THEOLOGY*, 2013;9(4):1-9. **'Secular bioethics and euthanasia in a democratic public space.'** In democratic societies, the euthanasia debate involves, apart from personal decision and deontological issues, institutional mechanisms of communication, regulation, control and action. The religious and secular reflection on euthanasia involve two different ways of understanding human nature, the meaning of life, of suffering and of death. From the side of bioethical debate it is hard to unify them. However, what matters is that they do not get into conflict and leave room for a democratic choice, as regards personal choices and institutional rules. In the cultural spaces of the Western societies where euthanasia is permitted, the theoretical options have also existential relevance because they shape our way of understanding responsibility towards ourselves and others. http://www.ejst.tuiasi.ro/Files/40/1_Frunza.pdf

Media Watch Online

Asia

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

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

Australia

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

Canada

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

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

ONTARIO | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.palliativecareconsultation.ca/?q=mediawatch>

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

Europe

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

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

International

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

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

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

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